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ABSTRACT

This manual contains materials for a course designed to enable Nashville high school students to develop peer relationships while acting as peer buddies and positive role models for students with special needs. Information is provided on various types of disabilities and learning problems, instructional techniques for students with disabilities, and ideas on how to help increase the social skills, interactions, and participation of peers with special needs in the day to day activities at school and in the community. The course is designed to be taken as an elective for one half a credit per semester, one class period per day. The maximum number of credits typically received in the course is two. Specifically, the course addresses: (1) the peer buddy's role; (2) peer buddy orientation; (3) evaluations and forms; (4) special education services; (5) guidelines for appropriate language; (6) task analysis; (7) dealing with inappropriate behavior; (8) mental retardation; (9) learning disabilities; (10) visual impairments; (11) hearing impairments; (12) speech and language disorders; (13) autism; (14) physical disabilities; and (15) attention deficit disorder. Disability-related Web sites are also provided. (Contains 16 references.) (CR)

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PEER BUDDY MANUAL

ED 432 109

METROPOLITAN NASHVILLE PEER BUDDY PROGRAM

Carolyn Hughes, Ph.D.
Carol Guth, Judith Presley,
Stacey Scott, and Sarah Lorden

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EC 307 314

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PEER BUDDY MANUAL

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I. Course Description

- Metropolitan Nashville Peer Buddy Program Introduction
- Peer Tutoring Course Description
- "Becoming Friends"

METROPOLITAN NASHVILLE PEER BUDDY PROGRAM

So, you've chosen to become a Peer Buddy! We think you made a wise decision. By participating in the Peer Tutoring Course you are likely to:

* make several new friends
* have a significant influence on someone's life and
* enjoy several new experiences which may help you make career choices.

You may be somewhat anxious about where to start. This handbook will give you several tips about how to initiate a relationship with your partner and how to motivate your partner to achieve the goals you set together. It will give you extra ideas and activities you may want to try with your partner. The handbook also provides background information about different types of disabilities, the field of Special Education, and introduces you to some special students and the important people in their lives. Remember, your supervising teacher will help you decide what goals you will help your partner work toward and how best to help him or her achieve those goals.

We want you to keep a log each day about your activities with your partner, your feelings about the time you spent together, and any questions or concerns you may have. Review this log with you supervising teacher each week, and this will give you another opportunity to learn some new ideas to try.

Have fun and remember you are about to meet some very special people!

PEER TUTORING HIGH SCHOOL COURSE

METROPOLITAN NASHVILLE PUBLIC SCHOOLS

Course Description: Course #SST5800Y(F)(S)

This course is designed to enable students to develop peer relationships while acting as peer buddies and positive role models for students with special needs. The buddies will receive instruction about various types of disabilities and learning problems, instructional techniques for students with disabilities, and ideas on how to help increase the social skills, interactions, and participation of their peers with special needs in the day to day activities at their school and in their community. The course can be taken as an elective for 1/2 credit per semester, one class period per day. The maximum number of credits that typically can be received in the course is two.

Qualifications:

Students must meet the following criteria: (a) an interest in the peer tutoring program, (b) an adequate GPA, (c) good attendance, (d) a recommendation from a teacher or counselor, and (e) their program of studies allows for an elective course (preferably 11th and 12th graders).

Requirements:

Students acting as peer buddies will report daily to an assigned special education teacher. The peer buddy, teacher, and partner will discuss and decide on an activity or assignment in which the buddy and partner will participate. The peer buddy will be required to keep a daily journal, complete weekly and/or six-weeks assignments, complete reading assignments from the Peer Buddy Handbook, and maintain good attendance.

Benefits peer buddies may receive from the Peer Tutoring Course:

* They will develop teaching and study skills.

* They will practice academic and social skills.

* They become advocates and learn valuable advocacy skills.

* They are provided with realistic career exploration for education or human service professions.

* They gain an impressive extracurricular activity for college applications or resumes.

* They gain in self-esteem by knowing they have enriched others' lives.

General Program Information:

This program has been approved by the Tennessee Department of Education. The program is designed as a step toward inclusion and integration of all students into the regular day to day activities of high school life. McGavock High School was the first Metro school to participate in the peer tutoring program in 1994. During the 1996-1997 academic school year, the following high schools will also participate in the program: Glencliff, Hillsboro, Hillwood, Overton, and Stratford. The remaining comprehensive high schools will offer the course in the 1997-1998 academic term.

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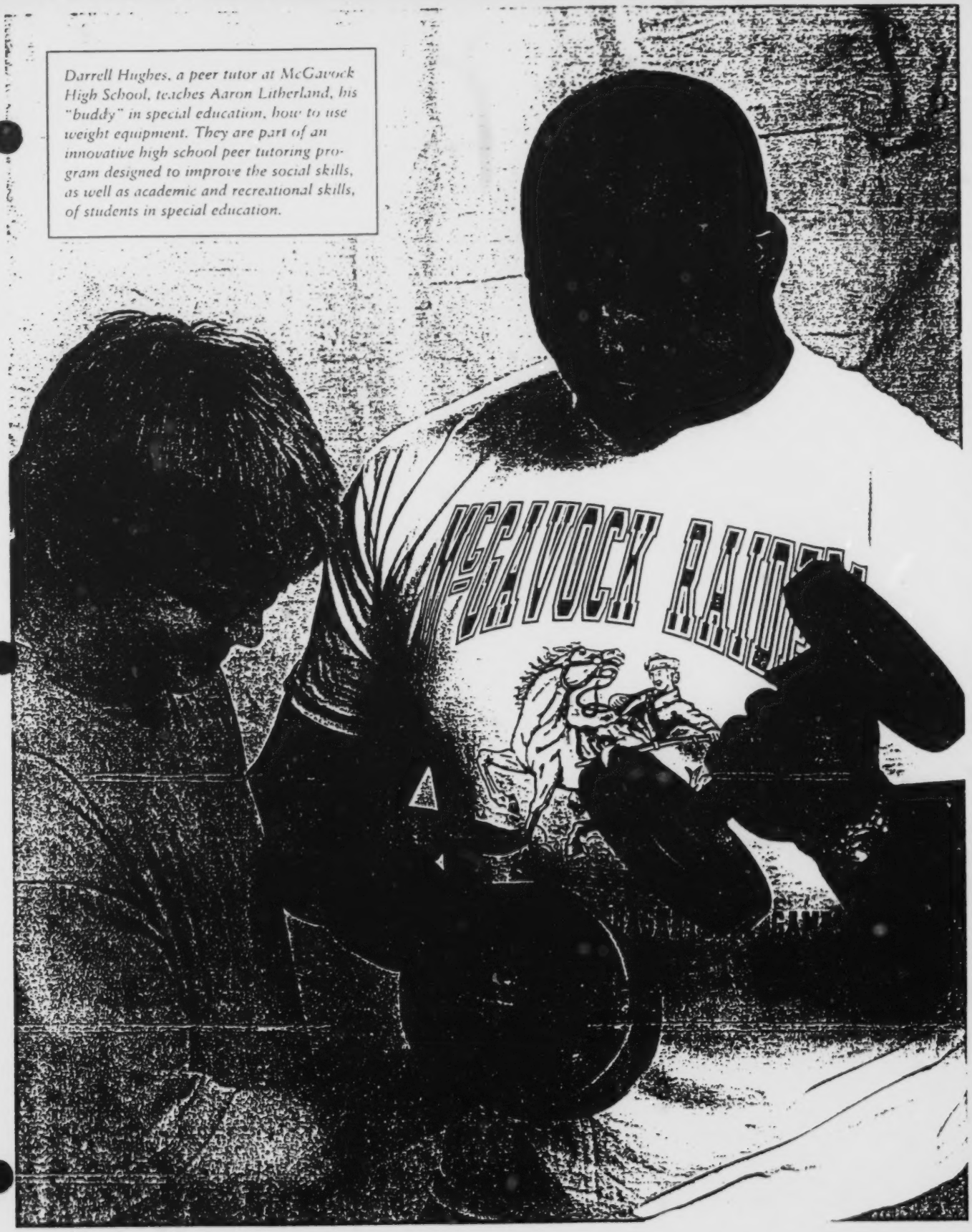

Darrell Hughes, a peer tutor at McGavock High School, teaches Aaron Litherland, his "buddy" in special education, how to use weight equipment. They are part of an innovative high school peer tutoring program designed to improve the social skills, as well as academic and recreational skills, of students in special education.

BEST COPY AVAILABLE PEABODY

Becoming Friends

A Peabody special education team helps unite "exceptional learners" in a Nashville high school's regular classrooms.

BY JAN ROSEMERGY

"This course is designed for students to serve as peer tutors and positive role models for special needs students at McGavock High School." So begins the description of "Nature and Needs of the Exceptional Learner," a new one-credit course that is making dramatic changes in the lives of special education and regular education students at this large, comprehensive high school. The course is just the latest chapter in the effort of Carolyn Hughes to help teens and young adults with disabilities make the transition from school to work and independent living in their communities. It also demonstrates how researchers and teachers together can develop creative solutions to learning problems.

In 1991 Hughes came to Peabody where she is assistant professor of special education and a John F. Kennedy Center investigator. Wanting to continue her research on a self-instructional strategy to teach students with mental retardation how to solve problems and sequence tasks, she visited McGavock High School where she met Gladys Henderson, who teaches students with severe disabilities. When Hughes asked her what kind of practical learning problems she might help solve, Henderson said that the most serious problem was students' lack of social skills.

"At first I didn't want to get involved because I didn't feel that this was my area of expertise," said Hughes. "But then I thought how important it was that a teacher had identified this major problem, and I believe that researchers really should listen to what practitioners have to say." So Hughes took her lead from these teachers and students and over the next two years developed methods for using the self-instruction technique to improve students' social interaction.

Now, through a three-year grant from the Tennessee Developmental Disabilities Council, Hughes and her colleagues are assisting McGavock High School teachers in establishing a "Peer Buddy" program. McGavock is the largest high school in Tennessee with more than 2,700 students and more than 300 students in special education programs. The school has four self-contained special education classrooms.

"Rather than have researchers—project staff—teach social skills, we had peers from the regular ed classes who volunteered," Hughes explained. "We had about 50 students involved in each of these studies that took place over two to three years. I became convinced of the value of peers as models for students with disabilities."

The program is unique in the Nashville school system, and in fact is one of the few in the country to use peer tutoring to support inclusion on the high school level among students with severe disabilities. Most inclusion efforts focus on preschool or elementary school students, and with students with less severe disabilities.

Although volunteer peer tutoring was having beneficial effects, a major barrier was the demanding, inflexible scheduling typical of high schools. Students lacked free periods and so were limited in the time they could volunteer. Again, cooperative, creative problem solving was the answer as researchers, teachers, counselors, and principals worked with the School Board and the State Department of Education to gain approval of a peer tutoring class, for which students earn .5 or 1.0 credits. The course was approved in fall 1994.

Hughes praises the support of McGavock High School's principal, Dr. Howard Baltimore, and the guidance counselors. "Without their help, I don't know that we would ever have gotten the peer tutoring program off the ground," she said. They let students know that the course was available, including announcing it on the school's closed circuit TV. Hughes and the McGavock staff also have worked with Future Teachers of America and other high school groups to recruit peer tutors.

After a referral from a guidance counselor, students complete a brief written application and have an interview with the teacher and student(s) in the special education class with whom they have chosen to work. The teachers believe this screening process is critical to ensure a good match between peer buddies and their partners with disabilities.

Regular education students who register for the course are assigned to one or more special education students. Peer buddies and their partners spend at least one class period a day together attending a regular education class (ranging from computer skills to horticulture, art, cosmetology, or history), interacting in a special education class, visiting the library, or attending Student Council, clubs, or other extracurricular and social events together. Peer buddies and their partners also meet once a week to have lunch together in the cafeteria. This "Lunch Bunch" is a purely social gathering and is joined by other regular education students who are interested in social inclusion but unable to enroll in the course because of class conflicts.

Once a week, peer buddies also meet with their

Peabody Reflector, Vol. 66 No. 1, Winter 1966. Published by Peabody College of Vanderbilt University. p. 3.

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That students with severe disabilities initiating social interaction is an indicator of the success of the peer tutoring program...

supervising teachers for assistance in setting goals with their partners and in developing strategies to meet their partners' special needs. Project staff provide technical assistance and support to the teachers, peer buddies, and administrative staff to promote social inclusion for each student with severe disabilities.

Hughes has developed a peer tutoring manual, which includes chapters on the tutor's role, sample activities and lesson plans, evaluation forms, introduction to special education services, and information on mental retardation, learning disabilities, visual impairments, hearing impairments, and speech and language disorders. Tutors keep daily logs and answer directly to the teacher in the classroom in which they've been placed with their special education peers.

Not surprisingly, the evaluations of the peer tutors indicate that experience is the best teacher. George Malone, a junior who has been a peer tutor, said, "I really cannot say I felt prepared, but I did not feel scared about doing it. It is just like when you first get married or have a baby. You do not really feel prepared or know exactly what to expect. But when it is time to do it, you do it without any problems. You learn how to really be a peer tutor by actually doing it. You learn what works and what does not."

Hughes emphasized that severity of disability has not been a barrier. "Students involved have a whole range of disabilities. Some have physical disabilities, others have autism and are nonverbal. That doesn't prevent interaction with regular ed students."

The social isolation of students in special education was most apparent in the school lunchroom, Hughes said. "Before, special ed students were in one corner, all at their own tables, and regular ed students were everywhere else. Now special ed students don't look special any more," Hughes said. "They are mingling with the regular ed students, and not just their peer buddies. They're taking the initiative to actually go up to a table and start chatting and sit down." That students with severe disabilities are initiating social interaction is an indicator of the success of the peer tutoring program, since generalizing skills across settings and independently using a skill are difficult for students with severe disabilities to achieve.

As a result of the peer tutoring, students from special education classes are getting out into regular education classes, the library, or the weight room, into extracurricular activities like clubs, student council, sports events, and the day-to-day things in which all other students take part.

"Without any direct instruction in social skills," Hughes said, "the students with disabilities are getting confidence through the modeling of the regular ed students. When they're together, the peer tutors tell them about their own lives. For example, one is a cross-country runner and she talks about this." Students in special education learn a whole new range of activities they can talk about and share.

Hughes has found that regular education students interact with their buddies on their own, not just during the "official" class period for credit. "That just seems to be an impetus," she said. "Some of them eat lunch with them daily, hang out with them in the halls at the lockers, and after school. It's a starting point for friendships."

About 15 students have registered for the peer tutoring class so far this year, but with other volunteers a total of about 40 regular education students are currently involved.

Hughes acknowledged that the project has required a lot of work, and the research staff continues to play an important role. She is assisted by project coordinator Carol Guth and graduate assistants Stacey Scott, and Judith Presley. There is one staff member at McGavock four days per week. "It's all so new to teachers," Hughes pointed out. "Many regular education teachers haven't had students with mental retardation in their classrooms." It's also difficult for classroom teachers, special or regular education, to have the time to work one-on-one with a peer and a buddy.

The research staff have helped problem solve situations, for example, how to accommodate a special education student in a regular ed classroom. "Sometimes we've met with a teacher and together developed alternate ways for an assignment to be completed," Hughes said. "All the teachers involved value what the students are doing and feel it would not be possible to have students with severe disabilities in the regular education classroom if there were not peers accompanying them."

Teacher evaluations document the positive changes they've observed in students with disabilities, for example, less inappropriate behavior, improved impulse control, improved attention, socialization, becoming more cooperative, and staying on-task more frequently.

Hughes devotes roughly half of her time to the project and has three half-time graduate assistants involved. She also works with an advisory board that includes a member of the Tennessee Developmental Disabilities Council, two regular education and two special education teachers, and a student with disabilities and her mother, all of whom have made important contributions to the project.

Hughes points out the potential vocational benefits of improved social skills. "One of the main reasons why people with severe disabilities are often not successful in integrated settings like work and living in the community is because they don't have the social skills we typically would expect." As a large, comprehensive high school, McGavock offers a wide range of vocational courses, from pipe fitting, secretarial work, to the restaurant trade. "We'd like to expand the peer-buddy program into the vocational classes," Hughes said.

The effects of the peer tutoring project are being evaluated in a variety of ways. At the end of the school year, the research staff interviews peer tutors, their buddies in special education classes, and teachers in the regular and special education classrooms. Information gathered in the first year has been used to improve the program. Students keep daily logs, and the research

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staff members observing at the school also keep logs. Data are kept on interactions and initiations by the peers and their buddies.

"We're looking at this as a kind of large case study," Hughes said. "What does it take to start up a peer buddy program in a large, comprehensive high school?" Due to a three-year grant from the Tennessee Developmental Disabilities Council, Hughes will be replicating the project in other area high schools. The goal is to expand to all Nashville high schools by providing materials and workshops. The project currently is in the first year of the grant.

Hughes has found at conferences and workshops that teachers are interested and eager for information on how to establish a peer tutoring program.

For Hughes, "one of the thrilling effects is that the regular ed students get as much out of it as the special ed students in learning about their own abilities and getting to know students whom they hadn't interacted with before."

Laurie Wood, a senior who was a peer tutor, said, "I really did not understand people with disabilities. I felt sorry for them. I did not know what they were thinking or feeling. I never had much contact with people with disabilities. I was afraid of becoming friends with them. Now I know that each one has his or her limits and abilities. They are like becoming friends with anyone else."

COMING FULL CIRCLE

Daniel Aguila is animal caretaker at the John F. Kennedy Center's Institute for Developmental Neuroscience. It's important work. The animals must be fed and watered regularly and precisely every day, their cages cleaned and washed, in accordance with stringent national standards of animal care.

That Daniel does his job well is not a surprise to his former employer, a pet store owner who recommended Daniel as the best employee he had ever had in that position. But it might be a surprise to some people because Daniel has Down syndrome. As a society we are a little slow at learning that people with disabilities, including persons with mental retardation, are hard-working, good employees.

Daniel is one of many staff members with disabilities who have been hired at Vanderbilt, with the help and support of the Opportunity Development Center, the Office of Recruitment and Staffing in Human Resources—and supervisors who realize that persons with disabilities are productive, reliable employees.

When the animal caretaker position became vacant, Mark Maguire, coordinator for Neuroscience Services, was interested in hiring a person with a disability and contacted Goodwill Industries. Daniel had been laid off from his job at Jones's Pet Shop when it closed in 1994, so he was available and had relevant experience. When Daniel was hired in July 1995, he worked closely with Mark and a Goodwill job coach to learn what to do.

After four months in the lab, Daniel is doing well in carrying out his job responsibilities under Mark's supervision. At his desk, Daniel has simple checklists for his different responsibilities each day of the week. He takes pride in giving a visitor a tour, explaining his work, and showing off his lab coat. He likes feeding and watering the mice and rats and has learned to hold them by their tails to avoid scratches when moving them to clean cages. Cleaning cages is hard work, he says, but he likes to sweep and mop—chores he does at home, too. With help from his job coach, he's learned the bus route between work and home and now travels to and from work independently.

Some of the animals that Daniel cares for are a strain of mice that have the genetic equivalent of Down syndrome. Researchers here who work with this animal model for Down syndrome have begun a collaboration with researchers at the University of California at Riverside who study Down syndrome in humans in order to advance knowledge of plasticity—the brain's ability to change.

Like other young adults, Daniel has leisure activities he enjoys. He swims at the YMCA, where he also likes helping the young children learning to swim. He is an acolyte at Blakemore United Methodist Church. His heros are Jason Kingsley, a young man with Down syndrome who appeared on Sesame Street, and Chnstopher Burke, an actor with Down syndrome.

Daniel's story truly begins not a few months ago but more than 20 years ago when he was a toddler in the pioneering Toddler Research and Intervention Project at the Kennedy Center's Susan Gray School (then called the Experimental School). There Daniel was in a preschool class with children with developmental delays and typically developing children. Kennedy Center researchers found that educating children with and without disabilities together benefited both groups of children—and these findings helped pave the way for IDEA, the Individuals with Disabilities Education Act, which entitled all children to an appropriate public education.

Daniel's mother believes that her son's success today is related to the good, early start he received at the Kennedy Center. She says, "We've come full circle."

Jan Rosemergy

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II. The Peer Buddy's Role

- Excerpts from the Governor's Study Partner Program from the Tennessee Department of Education

THE GOVERNOR'S STUDY PARTNER PROGRAM

• TUTOR'S MANUAL •

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Tennessee State Department of Education

How to

Introduction

The students being tutored in this program often feel locked out of the learning process. One reason for this feeling is not knowing how to tackle an assignment. Good study habits are the most important key to learning.

On the following pages you will find suggestions and examples for developing study skills. These suggestions are not to preach or teach; most of your study partners have heard it all before. They have not, however, learned or practiced good study habits. Using these skills as you work together may be your biggest contribution to your study partner's increased success in school.

Leaning is an active process. We learn through watching, listening, thinking, reading, practicing and doing. Your positive attitude and positive behavior will be more important than anything you can say. You cannot study for your partner, but you can guide the studying process and set an example.

Good News! Your study skills might be strengthened, too.

Tutor Tip

Beware! Doing homework is not necessarily the same as studying. Tips for getting the most out of homework are included in this section, but your goals are bigger than that. Spending your tutoring time on completing homework alone would be like choosing to eat one doughnut instead of owning the bakery.

MOTIVATION

The M work is a major reason for success in school and later in life. The lack of it is a major reason for failure. Many tutors have reported this to me with great alarm - "my study partner doesn't care." Several things should be said at this point. Some tutor tips:

✎ I don't care often is a cover-up for <u>I don't know how.</u> Struggling students get further and further behind until they reach a point that they do not know the question to ask - - much less the answer. They act as if I don't care.

✎ Motivation is <u>caught</u> more than it is <u>taught</u>. Your motivation may rub off. Your study partner's interest in school work may be increased because of your interest in him as a person.

✎ Relationships have a lot to do with our own reason to be motivated. Think briefly about your own school experience. What teachers are you most anxious to please? When do your put extra effort into your work? In what classes do you care more about your performance? How much did your answers have something to do with your relationship with your teachers? Probably a lot!

✎ Goals also play a big part in motivation. They keep us on track - going in a certain direction. Your study partner may have very few if any goals. Thus, he or she may have little or no direction and motivation - more about this when we talk about goal setting.

✎ The M work is greatly connected to ones interest. We actually work harder in areas we like. While I am highly motivated about football, driving many hours to see a game, I would not walk across the street to see a hockey match - but many would! Find areas of interest that your study partner may have. If there is motivation in one area - there is hope for motivation in another. I could learn to be motivated about hockey. A previous tip may also apply - I don't know may be a reason I don't care about hockey.

The Relationship

The R word is the key to being a successful tutor. It requires work, sweat and even on occasion tears. This is the reason the G.S.P.P. requires a one on one tutorial relationship. If "Sam" has a different tutor each time they meet it is very difficult for any "bonding" to take place. "Sam" needs more than a tutorial pool - he needs one individual with whom he can become a friend.

The Tutorial Rule

Be a friend first, tutor second and never the teacher.

Tips for the relationship

✎ Get to know Sam. Find out his interest/likes, dislikes/hobbies. Use the interest inventory to get you thinking. It is not designed for you to hand out to Sam saying "Fill this out, I'll be back to get it in 10 minutes."

✎ Keep in contact with Sam - This is not tutorial time - but in the hall, at lunch, or on the bus. If Sam says, "I can't come to our study this time, Aunt Matilda fell out of a barn over at Bucksnort and broke her big toe. We have to go see her." What should you say when you see Sam again? (Answer - "How's Aunt Matilda's toe?")

✎ Be patient with Sam - Your study partner may not - most likely - react as quickly as you do. Learning may not be as easy for Sam. His learning may be distracted due to other problems in his life. This will require work on your part unless you are one of the lucky ones born with a lot of it. It will be worth the effort - your character may be strengthened.

✎ Be positive with Sam - Show him what is right with his work - How can you say - you've got this wrong without saying you've got it wrong? "Let's do it again" is a good statement. Show progress that is being made - praise when success happens. Sam has had enough negatives. Positive reinforcement will help your study partner to "feel good" - I can will lead to I DID! Beware that the negative also works - I can fail may lead to I DID FAIL!

✎ Always exhibit a caring attitude! I care about you: I want you to do better in school. Remember the vehicle that carries what you know to your study partner is a caring spirit. **YOUR STUDY PARTNER NEEDS TO KNOW YOU CARE** before they will care about what you know. Your success as a tutor is not dependent upon how much you know, but rather how much you care.

TECHNIQUES OF TUTORING

- **BE POSITIVE NOT NEGATIVE.** Place yourself in your study partner's situation. Sincere compliments always work better than embarrassing criticism. Drop "no" from your vocabulary.

- **BE COURTEOUS AND THOUGHTFUL.** This includes starting and stopping a lesson on time and being attentive to your study partner's conversation about himself and his personal problems. If you're willing to listen, you'll be amazed at how much he can teach you.

- **USE HUMOR TO MAKE THE SESSION FUN.** Never hesitate to admit a mistake or that you don't know something. It can be a great learning situation together.

- **BE PATIENT.** We all require understanding from others, and learning can be difficult when other problems in our lives also demand attention.

- **UNDERSTAND** that every learner has a lot of experience, information and knowledge even though his formal education may not have been adequate.

- You will often be the one who provides the encouragement to continue. **DISCUSS THE PROGRESS YOU HAVE MADE**, and write down what has been learned. It helps your study partner see his progress toward his goal.

- **BE FLEXIBLE.** Never think that because you've started one method that changes cannot be made. Think about the way your study partner learns best. Maybe he needs information now that you planned for later. Maybe he needs more of a challenge or a different approach. Remember that people learn differently. It's helpful when writing, listening and reading are all used, but it's up to you to find out what does succeed.

- **MAKE SURE** every lesson not only contains challenging work for your study partner but also contains enjoyable material that can be successfully handled.

- **YOUR STUDY PARTNER SHOULD UNDERSTAND WHAT HE IS TO DO.** It is easy to say too much, so say enough to be clear, then provide time for questions. Let him practice with the material before working on his own. Writing down the assignment helps.

- **LET HIM PARTICIPATE, NOT JUST LISTEN.** Having him correct his own papers will help him learn what needs to be worked on.

- **YOU ARE GUIDING YOUR STUDY PARTNER INTO INDEPENDENT LEARNING.** Everything you do should lead to that. Be glad when he tells you that something isn't working. That can mean he is analyzing some of his own learning needs.

- **REVIEW FOR RETENTION.** Practice is good, but don't do so much of it that it becomes unthinking behavior just to finish a page. However, allow for enough practice to learn the skill.

- **ALWAYS BE ALERT** to any problems needing special attention, such as hearing or visual difficulties.

INTEREST INVENTORY

NAME: _____

1. The things I like to do after school are:

2. The television programs I enjoy most are:

3. My hobbies are:

4. If I could take a trip, I would like to go to:

5. My favorite real-life hero is:

6. My favorite make-believe hero is:

7. The school subjects I like best are:

8. I like to read these types of stories:

SPORTS: Circle the sports you enjoy doing.

baseball	fishing	ice skating	swimming
basketball	football	jogging	tennis
bicycling	golf	roller skating	wrestling
bowling	handball	skateboarding	volleyball
boxing	hockey	soccer	other _____

INTERESTS: Check things you would like to know more about.

art	detectives	mystery	television
auto mechanics	electricity	race cars	woodwork
basketball	famous people	riddles	other _____
comic books	football players	rock stars	
cowboys	music	stories about people	

Getting To Know You

USE THESE QUESTIONS TO GET TO KNOW YOUR STUDY PARTNER BETTER!

- Where were you born?
- How many are in your family?
- What do you do in your spare time?
- What kind of work do you do?
- Why did you take this course?
- What would you most like to gain from this course?
- What are four accomplishments that you are proud of?
- What is your favorite TV program?
- What were the best and worst things that happened to you last year?
- If you could change just one thing about this world, what would it be?
- What has been your most embarrassing moment?
- What is your favorite color and why?
- What makes you angry?
- Who is your favorite person?
- If you could trade places with someone, who would it be?

I Am . . .

- These things make me feel important, for example: making a good grade or getting a compliment.

- My favorite hobby is:

- I am good at (my best talent or skill is):

- My favorite school subject is:

- One of the most difficult things I have ever done is:

- I feel cared about or appreciated when:

I AM GOOD,
BUT I AM ALSO GETTING BETTER!

KNOW WHERE YOU WANT TO GO

Setting Goals

Goal setting should be an ongoing process **guided** by the tutor. As one goal is achieved it should be replaced by another goal. The study partner and the tutor should make their goals achievable. A reminder: The goals should be set by the study partner, who may have somewhat different goals from those the tutor might set. These points should be considered when setting realistic goals:

- Goals must be realistic - This is **very** important because the purpose of goal setting is for Sam to reach one. Setting a goal and reaching it is success. There are some things your S.P. can do that are not related (but they really are) to A B or C. Sam can:
    a. Come to class every day next week
    b. Come to class on time
    c. Come to class with his stuff - paper, pencil, book and assignment
    d. Do his homework on time

- Goals must be of short duration - Shorter the better. If the goal is realistic - Sam should reach it. (How can we know what Sam can do - remember previous tutor tips.) Success produces success. Praise your S.P. and then set another goal.

Setting and reaching of goals can be a very effective tool in the breaking of the cycle of failure. Nothing succeeds like success!

Don't Quit

When things go wrong, as they sometimes will,
When the road you're trudging seems all uphill,
When the funds are low and the debts are high,
And you want to smile, but you have to sigh,
When care is pressing you down a bit ~
Rest if you must, but don't you quit.

Life is unstable with its twists and turns,
As every one of us sometimes learns,
And many a person turns about
When they might have won had they stuck it out.
Don't give up though the pace seems slow ~
You may succeed with another blow

Often the struggler has given up
When he might have captured the victor's cup;
And he learned too late when the night came down,
How close he was to the golden crown.
Success is failure turned inside out ~
The silver tint of the clouds of doubt ~
So stick to the fight when you're hardest hit ~
It's when things seem worst that you mustn't quit.

III. Peer Buddy Orientation and Sample Activities

- Peer Buddy Orientation
- Sample Activities

PEER BUDDY ORIENTATION

1. Peer buddy comes to special education classroom during the designated class period for the first few days (1-5 days):

   A. Teacher talks about specific disability (characteristics of learning and behavior, specific to the students in the classroom).

   B. Peer buddies participate in various activities in the room and meet all of the classmates. Peer buddy may then choose a first and second choice for a partner to work with, or a partner may be chosen for them.

   C. Peer buddy and partner meet each other (with teacher prompts if necessary).

   D. Peer buddy and partner engage in a desired activity together in order to get acquainted. This is a good chance to observe behaviors.

2. Teachers train peer buddies (1-3 days):

   A. Peer buddies' role (commitment, what is expected of them, etc.).

   B. Tasks and materials (identify skills the partners need to work on and ways the teacher addresses these skills).

   C. Appropriate means of giving directions, reinforcing, addressing inappropriate behaviors, and giving feedback.

   D. Teacher individualizes instruction for each partner, including skills and subject areas that need to be worked on. The peer buddies then pick the areas that they are interested in presenting to their partners. Once the activities are discussed, the teacher helps the buddy evaluate what skills his or her partner needs to learn (i.e., telling time, coin recognition, using sentences, initiating conversation, etc.).

   E. Teacher then demonstrates the activity. The peer buddy practices, is observed, and given feedback.

   F. Teacher and peer buddy discuss opportunities for social activities and social skills training.

Adapted from the Tennessee LRE for Life Project

SAMPLE ACTIVITIES

The following pages give several examples of goals, instructional plans, and activities designed to prepare individuals with disabilities to lead productive and personally satisfying adult lives. These are included to give you some ideas for helping your partner set appropriate goals and work toward their accomplishment.

The first item is a two page chart which categorizes important life skills into three major curriculum areas and delineates competencies which fall under each of those domains.

Next are samples of instructional plans designed to teach specific skills, such as coin identification and making correct change.

Following these are a variety of suggestions for activities you may want to try with your partner, activities which will also teach valuable social skills and leisure skills.

FIGURE 2-2
Life Centered Career Education Competencies (Revised 1/87)

Curriculum Area	Competency	Subcompetency: The student will be able to:	
DAILY LIVING SKILLS	1. Managing Personal Finances	1. Count money & make correct change	2. Make responsible expenditures
	2. Selecting & Managing a Household	7. Maintain home exterior/interior	8. Use basic appliances and tools
	3. Caring for Personal Needs	12. Demonstrate knowledge of physical fitness, nutrition & weight	13. Exhibit proper grooming & hygiene
	4. Raising Children & Meeting Marriage Responsibilities	17. Demonstrate physical care for raising children	18. Know psychological aspects of raising children
	5. Buying, Preparing & Consuming Food	20. Purchase food	21. Clean food preparation areas
	6. Buying & Caring for Clothing	26. Wash/clean clothing	27. Purchase clothing
	7. Exhibiting Responsible Citizenship	29. Demonstrate knowledge of civil rights & responsibilities	30. Know nature of local, state & federal governments
	8. Utilizing Recreational Facilities & Engaging in Leisure	33. Demonstrate knowledge of available community resources	34. Choose & plan activities
	9. Getting Around the Community	38. Demonstrate knowledge of traffic rules & safety	39. Demonstrate knowledge & use of various means of transportation
PERSONAL-SOCIAL SKILLS	10. Achieving Self Awareness	42. Identify physical & psychological needs	43. Identify interests & abilities
	11. Acquiring Self Confidence	46. Express feelings of self-worth	47. Describe others perception of self
	12. Achieving Socially Responsible Behavior	51. Develop respect for the rights & properties of others	52. Recognize authority & follow instructions
	13. Maintaining Good Interpersonal Skills	56. Demonstrate listening & responding skills	57. Establish & maintain close relationships
	14. Achieving Independence	59. Strive toward self-actualization	60. Demonstrate self-organization
	15. Making Adequate Decisions	62. Locate & utilize sources of assistance	63. Anticipate consequences
	16. Communicating with Others	67. Recognize & respond to emergency situations	68. Communicate with understanding
OCCUPATIONAL GUIDANCE AND PREPARATION	17. Knowing & Exploring Occupational Possibilities	70. Identify remunerative aspects of work	71. Locate sources of occupational & training information
	18. Selecting & Planning Occupational Choices	76. Make realistic occupational choices	77. Identify requirements of appropriate & available jobs
	19. Exhibiting Appropriate Work Habits & Behavior	81. Follow directions & observe regulations	82. Recognize importance of attendance & punctuality
	20. Seeking, Securing & Maintaining Employment	88. Search for a job	89. Apply for a job
	21. Exhibiting Sufficient Physical-Manual Skills	94. Demonstrate stamina & endurance	95. Demonstrate satisfactory balance & coordination
	22. Obtaining Specific Occupational Skills		

Chart continued on following page

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3. Keep basic financial records	4. Calculate & pay taxes	5. Use credit responsibly	6. Use banking services	
9. Select adequate housing	10. Set up household	11. Maintain home grounds		
14. Dress appropriately	15. Demonstrate knowledge of common illness, prevention & treatment	16. Practice personal safety		
19. Demonstrate marriage responsibilities				
22. Store food	23. Prepare meals	24. Demonstrate appropriate eating habits	25. Plan/eat balanced meals	
28. Iron, mend & store clothing				
31. Demonstrate knowledge of the law & ability to follow the law	32. Demonstrate knowledge of citizen rights & responsibilities			
35. Demonstrate knowledge of the value of recreation	36. Engage in group & individual activities	37. Plan vacation time		
40. Find way around the community	41. Drive a car			
44. Identify emotions	45. Demonstrate knowledge of physical self			
48. Accept & give praise	49. Accept & give criticism	50. Develop confidence in oneself		
53. Demonstrate appropriate behavior in public places	54. Know important character traits	55. Recognize personal roles		
58. Make & maintain friendships				
61. Demonstrate awareness of how one's behavior affects others				
64. Develop & evaluate alternatives	65. Recognize nature of a problem	66. Develop goal seeking behavior		
69. Know subtleties of communication				
72. Identify personal values met through work	73. Identify societal values met through work	74. Classify jobs into occupational categories	75. Investigate local occupational & training opportunities	
78. Identify occupational aptitudes	79. Identify major occupational interests	80. Identify major occupational needs		
83. Recognize importance of supervision	84. Demonstrate knowledge of occupational safety	85. Work with others	86. Meet demands for quality work	87. Work at a satisfactory rate
90. Interview for a job	91. Know how to maintain post-school occupational adjustment	92. Demonstrate knowledge of competitive standards	93. Know how to adjust to changes in employment	
95. Demonstrate manual dexterity	97. Demonstrate sensory discrimination			
There are no specific subcompetencies as they depend on skill being taught				

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LESSON PLAN 9 1.1.3P:9

LCCE Objective 1.1.3. Make correct change from both bills and coins for amounts less than or equal to $50.00.

Lesson Objective: Student will make the correct change for items purchased with $10.00, $20.00 and $50.00 bills.

Instructional Resources: Real or play money ($50.00, $20.00, $10.00, $5.00 and $1.00 bills, half dollars, quarters, dimes, nickels and pennies), store items with prices marked on them.

Lesson Introduction: Today each of you will role-play being a store clerk for the items that are displayed on this table. One person will be the salesclerk and another person will buy an item that has been marked with the sales tax included. The salesclerk will take the bill handed to him or her and count out loud the correct change to the customer.

School Activity: **Time: 1 session**

Task:

1. Display many differently priced items on a table. Place money in cash register or storage container.

2. Explain directions for role-play to students.
   - Students will take turns role-playing salesclerk.
   - Another student will select one of the items and purchase it with a $10.00 bill, then will buy an item with $20.00 and $50.00.
   - Salesclerk gives the correct change for each item.
   - Students who are observing should compute on a sheet of paper what they think the correct change should be.

Lesson Plan Evaluation:

Activity: Students will role-play customer and clerk in purchasing items.

Criteria: Student will make correct change for three priced items when role-playing the salesclerk.

Career Role: Family Member/Homemaker, Employee, Citizen/Volunteer, Avocational
Career Stage: Preparation

Sample Lesson Plan from *Life Centered Career Education: Daily Living Skills*, p. 27

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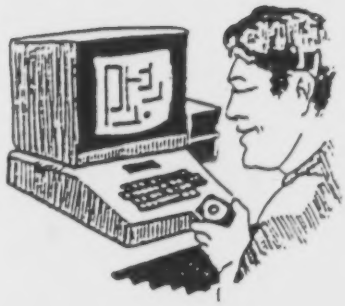
Computer games are a fact of the '80s!



Most schools have a computer lab or computers available through an instructional media center. Computer games offer a great opportunity for social interaction with regular student body members. Games can be educational too! Many have been designed to practice basic academic concepts.

While the particular procedures will vary as a function of the particular brand and model of computer, in general, the activity includes:

- Traveling to area
- Activating computer
- Selecting diskette with game(s) of choice
- Loading diskette
- Loading game
- Playing
- Down loading diskette
- Continuing to next activity

A picture card depicting the sequence of procedures to load/unload program makes this activity possible for most individuals.

Minimal skills are required and all levels of play are tolerated.

Responsive audio and visual displays interest many!

ITEM 1-2-1 Playing Computer Games

What Does a "Good" Goal Look Like?

Once we have selected an activity from *The Activities Catalog* to include on a person's individualized plan, we have to write it out as a goal. Writing the goal is the first step in translating an activity label into an intervention program.

A "good" goal statement specifies the target activity and describes what you expect the person to do as a result of the training or support. A "good" goal statement answers questions:

Where do I expect the person to perform? everywhere in the community or only in designated locations?

How much do I expect the person to do independently? all of it, or only certain steps while getting assistance on the others?

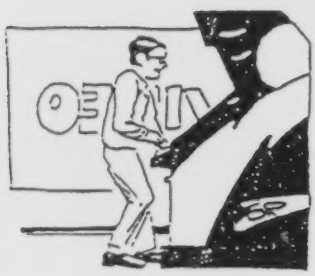
What steps will require modification and what kind of modification is likely?

What are other constraints or limitations I want to define?

General goals—"To improve vocational capacity," "To increase community leisure skills," or "To expand domestic competence"—really don't tell very much. A parent doesn't know what to expect. A teacher doesn't know how to design an appropriate intervention. A program manager doesn't know when important goals have been achieved.

Though it may seem complex, it is only by being clear about the intended goal that we can develop an appropriate intervention to achieve that goal.

Space Invaders! Donkey Kong! Pac Man!



What is more common these days than the whirr, blast, and bleep of the video game? It's everywhere and it's fun for children of all ages!

Video games present a great variety of sights and sounds. Play demands little strength or motor skill. The amount of time required is flexible—you can occupy a few minutes or an entire afternoon.

Activity includes:

- Traveling to video arcade/computer
- Selecting game
- Loading program/inserting coins
- Activating the machine
- Operating controls
- Continuing to next activity

There are important differences in coin-operated games and those games available on personal computers. Travel and expense is reduced with home play, while community visibility and social interaction are increased by play at stores, arcades, or community centers.

If you plan both computer and coin-operated play, it is important to examine the type of controls on various machines. Training machines with the same control mechanics should guarantee greatest initial success but may result in generalization problems if play expands to include still other machines.

ITEM 1-2-2 Playing Video Games
- a. On home/school computer
- b. At community location

Exerpts from: The Activities Catalog, An Alternative Curriculum for Youth and Adults with Severe Disabilities, Wilcox and Bellamy.

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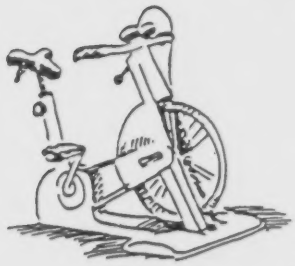

School. Home. Gym. There are many places where you can keep in shape (or get in shape) using exercise equipment.

This activity is limited only by the equipment available.

Activity includes:

- Changing into appropriate clothing
- Getting equipment from storage
- Using equipment
- Returning material to storage
- Showering and changing clothes necessary
- Continuing to next activity

Users will need minimum instruction specific to each type of equipment. Consider programs to increase length of exercise period.

ITEM 1-1-8 **Using Exercise Equipment**

a. Jump-rope
b. Rebounder
c. Exercise bike
d. Rowing machine

Physical fitness is a must for the 80s . . . and weight training is an increasingly popular way to keep fit.

This activity can be done alone or with a small group of friends. Providing assistance and encouragement to one another is an integral part of the activity.

Activity includes:

- Traveling to weight-training area
- Changing clothes
- Adjusting weights/machines
- Working out with weights/machines
- Showering
- Changing clothes
- Continuing to next activity

Membership dues or fees may be required at community locations.

A sequence of photographs can prompt correct positioning and use of machines, as well as specify an optimal order for exercises to be completed.

ITEM 1-1-9 **Weight Training**

a. High school physical education class
b. Community recreation center or fitness club
c. Private home

When I was forty, my doctor advised me that a man in his forties shouldn't play tennis. I heeded his advice carefully and could hardly wait until I reached fifty to start again.

Justice Hugo Black

Tennis, anyone?

A variety of racquet sports offer opportunities for individual or team competition . . . or simply good fun.

Each of these activities requires some specialized equipment: racquet, shoes, ball/birdie, and a special playing area. Racquet sports are good leisure options when playing areas are easily available or when others in the family or neighborhood have an active interest in the sport.

Activity includes:

- Identifying a partner
- Gathering necessary materials
- Travel to playing area
- Playing/volleying
- Returning to origin
- Returning material/equipment to storage
- Continuing to next activity

While most racquet sports require two players, tennis and racquetball can be practiced individually against a backboard.

ITEM 1-1-10 **Playing Racquet Sports**

a. Tennis
b. Racquetball
c. Ping pong
d. Badminton

Different Reasons . . . Different Goals

There are several reasons that you might want to include an activity on a person's IEP or IHP. Very often we choose activities because they are things we would like the person to learn. We call those *acquisition* goals.

Sometimes, though, we include activities that an individual can already do because we want to change some aspect of his or her performance. Those *performance* goals might focus on ensuring opportunities to participate or on changing the quality of the performance. Examples of quality change goals might include training or support to make performance more integrated, intervention to increase the frequency of an activity or to increase the variety of circumstances under which the activity could be done, training for choice over certain activity components, or training to make performance more independent.

In *The Activities Catalog* system, goals related to the performance of valued activities are considered just as important as goals that target new learning.

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Events

There's a club for everything: Music. Movies. Art. Politics. Social Service. Environment. Folk Dance. Dogs. Stamps.

Club membership is an ideal way to pursue an interest and make friends with those who share it. Some clubs will have formal, structured, activity-oriented meetings. Others will be less formal and less amenable to teaching. The nature of meetings as much as the general subject matter may influence your choice of clubs.

Activity includes:

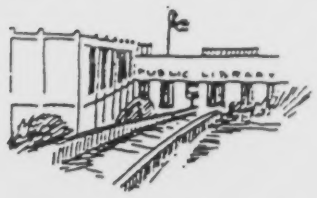
- Traveling to meeting location
- Participating in activities as appropriate
- Returning to next activity

Some clubs may require membership dues or activity fees.

The thing which is most outstanding and chiefly to be desired by all healthy and good and well-off persons, is leisure with honour.
Cicero

ITEM 1-3-1 Attending Club Meetings

Note: This activity can be combined with ITEM 2-4-1: Managing a Personal Schedule.



Today's library is a lot more than books. It's magazines, records, and cassettes. It's listening areas and comfy chairs. It's a place for lectures, presentations, and community affairs programs.

Going to the library is an activity for an individual, a family, or a group of friends. Time and skill requirements are flexible. There's something for everyone whether you've got a half hour or an entire afternoon.

Activity includes:

- Gathering necessary materials (library cards, books/records to be returned, etc.)
- Traveling to library
- Using library facilities (browsing, reading, listening to records/cassettes)
- Checking out materials if desired
- Traveling home/to next activity

Checking out books, tapes, or records will require a library card. Requirements for cards will depend on the community. A book bag or pack will be helpful to organize materials for transit.

ITEM 1-3-2 Using the Library

One ought, every day at least, to hear a little song, read a good poem, see a fine picture, and, if it were possible, to speak a few reasonable words.
Johann W. von Goethe

Why sit home? Pick your activity, time, and place—and GO!

Most communities offer a tremendous range of events—if you take the time to look for them. And the looking isn't hard: newspapers, radio, television, bulletin boards, and friends can tell you about more events than you could hope to attend.

Requirements for participation will depend on the event. Some may be pricey (movies, sports events, concerts). Others may have a modest admission fee (museums, fairs). Still others are free (parks, parades).

The components of participation will vary considerably as a function of the event selected. In general, however, attending a community event will include:

- Checking the time (and price!) of the event
- Dressing appropriately
- Gathering necessary materials (such as money, bus pass, or items necessary to enjoy the event)
- Traveling to the event
- Purchasing ticket if necessary
- Enjoying the event
- Traveling home/to next activity

Naturally, "enjoying the event" will require different behavior for different events. Sometimes it will mean sitting quietly and listening; other times, cheering loudly for the favorite team. Though some events, such as church and movies, have fairly standard routines, many other events have minimal or very flexible structures. The key to enjoying events is having someone in the group who will highlight the demands and expectations of the particular context.

Events are often seasonal or one-time-only affairs and consequently difficult to "train." But there *is* something for everyone!

ITEM 1-3-3 Attending Community Events

a. Church
b. Movies
c. Plays/concerts/performances
d. Sports events (high school, college, semi-pro, pro, community leagues)
e. Rodeo
f. Museums
g. Exhibits and shows
h. Fairs and festivals
i. Parks
j. Parades
k. Circus
l. Parties and dances
m. Scenic rides
n. Sightseeing trips

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Don't feel like cooking? Enjoy a quick meal out.

Fast-food restaurants have become part of our way of life. Once limited to hamburgers, shakes, and fries, fast-food establishments now offer an astonishing array of cuisines. They offer breakfast, lunch, and dinner—and, of course, snacks.

Activity includes:

- Preparing to go (checking appearance; getting money and other necessary materials)
- Traveling to restaurant
- Entering
- Placing the order
- Paying for purchase
- Carrying food to empty table
- Eating
- Cleaning up
- Traveling home/to next activity

Fast-food restaurants are *everywhere* . . . and they are different. You will need to decide which restaurants and which locations will be used. It will be necessary to devise a system for travel to each location, and to differentiate where one might walk or would need to be driven. The order of the routine may vary (in one you may get food and then pay while in another the order is reversed), so it is important that the trainer be familiar with the training sites.

It is desirable to maximize choice in this activity by devising a strategy that permits the individual to select the particular restaurant and his or her own meal. Several ways to adapt difficult steps of this activity support the participation of people with disabilities:

Use *menu cards* that picture the individual items available at the restaurant and their cost (rounded up to include tax if applicable).

Use a calculator and a *"Can I Afford It"* strategy for budgeting. The cost of the target meal can be added up and the necessary amount of money packaged prior to leaving for the restaurant. The menu cards themselves can double as communication cards in the restaurant.

Use a *next-dollar* strategy to pay for the purchase.

ITEM 2-2-1 Using Fast-Food Restaurants

Dining out. One of life's pleasures . . . and something we have come to associate with quality of life.

Activity includes:

- Preparing to go (checking appearance; gathering necessary materials; selecting restaurant; and so on)
- Traveling to restaurant
- Entering
- Waiting to be seated
- Ordering
- Eating
- Paying for meal (and tipping!)
- Traveling home/to next activity

Reservations are necessary at many restaurants, so it is important to know your dining establishments! If reservations are made in advance, it will be necessary to record the date/time on the individual's schedule or self-monitoring system.

Unlike fast-food establishments, patrons of sit-down restaurants are expected to leave a tip, so some strategy will be necessary to determine the size of the tip. Asking another patron to suggest an amount or requesting that the waiter compute a 15% gratuity on the bill are but two alternatives.

Establishing the particular restaurants an individual is to patronize regularly makes it possible to develop training materials to facilitate choice and budgeting.

ITEM 2-2-2 Using a Sit-Down Restaurant

Note: This activity can be combined with ITEM 2-1-1: Using Restrooms

Somewhere between fast food and four-star food is the cafeteria.

The cafeteria is an establishment in most schools and many businesses. If cafeteria-style eateries are commonplace in your community, it might be wise to know their rules!

Activity includes:

- Preparing to go (checking appearance; getting money and other necessary materials)
- Traveling to cafeteria
- Joining end of the line
- Getting a tray, utensils, and other materials
- Selecting food items
- Paying for purchases
- Transporting tray to table
- Eating
- Cleaning up
- Traveling home/to next activity

Eat, drink and be merry, for tomorrow ye diet
Lewis C. Henry

Perhaps the greatest danger of a cafeteria is selecting more than you can eat . . . or pay for! This can be handled by using menu cards to select items in advance from an array of items available, or by using a calculator and a cumulative subtraction strategy as you move through the line.

Those individuals who have difficulty carrying a tray will need a clear system for requesting assistance.

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Newspapers, magazines, and books are a common way of getting information and keeping up to date with the world around us.

You need *not* be a proficient reader to enjoy this activity. Just looking at pictures or scanning the headlines is quite normal.

Activity includes:

- Selecting a paper/magazine/book
- Finding a place to sit
- Orienting the material (right side up please!)
- Looking at the material; turning pages as necessary
- Returning paper/magazine/book to original location
- Continuing to next activity

For some individuals, training may focus on locating sections or information of interest (e.g., sports, weather, leisure events).

There are many opportunities to use this activity: at home, in the school or community library, in the doctor's waiting room, or in the break room. Time is flexible and cost minimal.

This can be an excellent way to respond to an individual's special interest areas.

ITEM 1-4-1 Reading Newspapers/Magazines/Books

Note: This activity can be nicely combined with ITEM 1-3-2: Using the Library, and reading materials can be purchased as part of ITEM 2-3-1: Purchasing Personal Items.

The newspapers! Sir, they are the most villainous—licentious—abominable—informal—not that I ever read them—no—I make it a rule never to look into a newspaper.

Richard B. Sheridan

What would life be without music? Or news? Don't force yourself to find out.

The radio is a readily available and inexpensive form of entertainment.

Activity includes:

- Locating radio
- Turning on equipment
- Adjusting the volume
- Selecting a station
- Listening to program
- Turning off equipment
- Returning radio to storage
- Continuing to next activity

Participation requires a radio—nothing more! And there is no limit on how long you can enjoy listening!

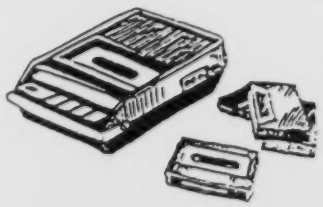
A small portable radio with headphones may be used to eliminate the monotony of work or exercise routines.

ITEM 1-4-2 Listening to the Radio

Music without the worry of records! Part of today's youth culture.

Activity includes:

- Locating cassette player
- Selecting a tape
- Inserting tape
- Turning on player
- Listening to program
- Changing tape as necessary/desired
- Turning off player
- Returning tape(s) and player to storage
- Continuing to next activity



All you need is a collection of tapes and a tape player. Players come in various formats, many of which are portable.

ITEM 1-4-3 Using a Cassette Player

Some men are so selfish that they read a book or go to a concert for their own sinister pleasure, instead of doing it to improve social conditions, as the good citizen does when drinking cocktails or playing bridge.

Jacques Barzun

Reading without books—enjoy a good story without straining your eyes!

You can be entertained by a good story while walking, riding in a car, or just relaxing.

This variation of using a tape player is available simply by purchasing books on tape rather than music.

These cassettes are available at bookstores or from the American Printing House for the Blind, 1839 Frankfurt Ave., Louisville, KY 40206 (502) 895-2406.

Books on tape and tape players are also available free of charge to qualified individuals through the Library of Congress, Library for the Blind and Physically Handicapped. Check your phone book for a local branch.

ITEM 1-4-4 Listening to Talking Books

Note: Individuals who enjoy playing records or tapes may want to consider related activities such as checking out records or tapes from the library (ITEM 1-3-2: Using the Library) or buying additional records or tapes (ITEM 2-3-1: Purchasing Personal Items).

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Developing Friendships

Friends are important to all of us. We each know that we just can't make it alone. We need the assistance, encouragement, and love of family, spouse, or friends. Individuals with disabilities are no exceptions.

Unfortunately, individuals with disabilities often have limited social networks. Their contacts are too often limited to other people with disabilities or to people who are paid caregivers (teachers, aides, group home providers, or attendants). Individualized planning meetings provide a natural time to think about what we can do to help people with disabilities make friends and expand that important social network.

The research literature on friendship has identified several factors that influence whether people become friends.

1. *Opportunities to interact.* Obviously folks can't very well become friends unless they have regular opportunities to interact and get to know each other. By selecting activity goals that put people with disabilities in regular contact with a social group, you are helping to build the basis for friendships.
2. *Image of similarity.* People are more likely to develop friendships with others who have shared interests and experiences. Selecting activities that are age appropriate and that take advantage of the opportunities available in a community highlights similarities between a person with a severe disability and his or her nonhandicapped peers. Doing things together builds a shared history and demonstrates shared interests.
3. *Competence.* People are more likely to become friends when they have the skills to initiate and sustain interactions. Concentrating on the social components of target activities will help build social competence for future encounters. In addition, having something to do together—going to a sporting event or to the corner café for coffee and a donut—represents another important form of competence basic to friendships.

Friendships don't develop in a vacuum but in the context of daily activities. While "having friends" is not an activity you can order from *The Activities Catalog*, you can increase the probability of friendships through the selection of activities that will provide the context.

If you are interested in a description of the kind of friendships that are possible between individuals with severe disabilities and folks without apparent handicaps, see the article entitled "Friendships and Our Children" by Jeff and Cindy Strully in the *Journal of the Association for Persons with Severe Handicaps* (1985, '6, pp. 224–227).

Sauna. Hot Tub. Whirlpool. Steam Room.

Once hard to find, these methods of relaxation are now common features in most gymnasiums, health clubs, and YMCAs.

Time in a spa is a great way to finish off a hard day of work or a well-fought game. Nothing, but nothing, erases the cares of the day or eases tired muscles like heat.

Activity includes:

- Gathering necessary materials (towel, suit, pass, etc.)
- Traveling to whirlpool/steamroom/sauna/hot tub
- Locating locker room/changing area
- Changing out of street clothes (and into suit or towel as desired as appropriate)
- Using whirlpool/steam room/hot tub/sauna
- Showering
- Changing into street clothes
- Gathering materials
- Traveling home/to next activity

Access to spas may require club memberships or fees. Prices will vary. Call ahead to determine hours, cost, and whether towels and lockers are provided.

ITEM 1-5-4 Using a Whirlpool/Steam Room/Hot Tub/Sauna

Get a perfect tan with—or without—the sun!

No doubt about it. A tan makes you look and feel good. And with today's technology, there's no reason to be pale. But don't overdo it!

Sunbathing is free . . . but requires the cooperation of the weather. Using a tanning salon ensures sun when *you* want it. The cost of tanning sessions will vary. Single sessions and packages are available. Call around to get the best price.

Activity includes:

- Gathering necessary materials (towel, sunglasses, and sunscreen)
- Traveling to salon/pool appropriate location
- Changing out of street clothes (and into suit)
- Tanning
- Changing into street clothes
- Traveling home/to next activity

Spas or salons will supervise the length of the tanning sessions, and will often supply towels, sunscreens, and moisturizers.

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Reach out and touch someone.

Not a bad idea. Calling nearby friends or family is an easy, inexpensive way to stay in touch, make plans, or relieve the boredom of the moment.

The activity of *making calls* includes:

- Locating telephone
- Dialing number
- Saying hello/requesting target person
- Talking/leaving message
- Saying goodbye
- Hanging up
- Continuing to next activity

Things haven't been the same since the fashion industry *and* high tech hit the telephone industry. Phones come in a staggering variety of sizes, shapes, and styles. Knowing how to operate one phone is *no* guarantee that you will be able to operate the next phone as easily! Consequently, effective training will require a careful review of the actual phones that will be available and a general case program to ensure the individual learning of a generalized skill. Training should focus on both making and receiving calls.

A personalized picture directory of frequently called people and numbers will eliminate the need to remember numbers or to struggle with the phone book.

The activity of *receiving calls* includes:

- Locating phone
- Picking up receiver
- Saying hello
- Responding to caller
- Saying goodbye
- Hanging up
- Continuing to next activity

There are many different ways of taking a message if a caller asks for someone who is not available to come to the phone. Strategies include writing from dictation, using a check-off form similar to those in use in many offices, turning on a tape recorder to record the message, or simply instructing the caller to "call again, please." The strategy should be determined prior to beginning training, and should, of course, consider individual skills and the preferences of the household.

ITEM 1-5-1 **Talking with Friends/Family on the Telephone**

a. Making calls

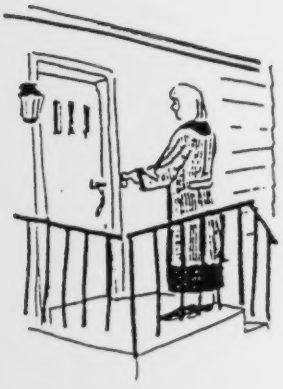
b. Receiving calls

Note: For further information, see Horner, R. H., Williams, J. A., & Steveley, J. D. (in press). Acquisition of generalized telephone use by students with severe mental retardation. *Journal of Applied Research in Mental Retardation.*

Liberty is being free from the things we don't like in order to be slaves of the things we do like.

Ernest Benn

A stroll down the block. A cross-country flight.
Do what it takes to keep in touch with family and friends.



In today's mobile society it takes effort and planning to maintain the social network that is so vital to each one of us. Visiting is a way to reach out, to expand horizons, to be on our own. Visits away from home are an important step in growing up.

Activity includes:

- Making arrangements for visit (establishing date, time, means of transportation, etc.)
- Gathering necessary materials (e.g., clothing, money, gifts)
- Traveling to target home/location
- Visiting
- Traveling home/to next activity

Naturally, transportation to and from visits can often be provided by family or friends, thus eliminating the need to train walking or bus routes. When walking or mass transit are the method of choice, sequenced picture cards can provide a clear reminder of the correct route. For long-distance trips by bus, train, or plane, preparations will be more extensive and more detailed provisions made to ensure supervision and assistance as necessary along the way.

ITEM 1-5-3 Visiting Family/Friends

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Managing your own schedule is perhaps the ultimate expectation of independence.

A personal schedule allows you to manage your time without necessarily having to tell time.

There are many ways to design a schedule to match the needs and skills of the user. A daily schedule can detail the morning routine, the schedule of tasks at work or school, and chores assigned at home. A weekly calendar can display appointments, special or nonrecurring tasks, or those activities scheduled less than once a week.

Individuals can assist in the selection and scheduling of leisure and personal management activities.

Schedules for home-based activities can be prepared weekly or adjusted each night for the following day. The schedule for work or school must, of course, be developed by people in those settings. Competent performance will be enhanced if a standard format is used across environments.

A picture of a clock face can designate *when* something is to be done and pictures or logos can replace written words to describe *what* should be done.

Activity includes:

- Locating personal schedule
- Matching time on clock to time on schedule
- Identifying activity associated with designated time
- Performing target activity
- Continuing to next activity

ITEM 2-4-1 Managing a Personal Schedule

Note: For procedures to teach self-monitoring, see Sprague, J., Mix, M., Wilcox, B., Styer, C., & Biber, E. (1983). Available from the Specialized Training Program, 135 College of Education, University of Oregon, Eugene, OR 97405.

Checks are both safer than cash and a necessity of modern life.

If you have an income or if you spend money, you probably need a checking account. Deciding where to bank is a matter of convenience and available services. The one-time-only task of opening an account is something that can be delegated to a family member/advocate.

Making a deposit includes:

- Gathering necessary materials (checkbook, cash and/or check)
- Traveling to bank
- Completing deposit slip
- Endorsing check if necessary
- Submitting money/check to teller
- Balancing account
- Returning home/to next activity

Making a withdrawal includes:

- Gathering necessary materials (checkbook, purse/wallet)
- Traveling to bank
- Writing a check
- Submitting check to cashier
- Receiving money
- Balancing account
- Returning home/to next activity

Writing a check includes:

- Gathering necessary materials
- Filling out check
- Balancing account
- Continuing to next activity

Competence on this activity is increased if there is intensive discrimination training on whether a situation requires deposit or withdrawal or can be handled by writing a check.

Many adaptations of this activity are possible for students who lack the academic skills typically associated with banking. For example, an advocate can complete the check/deposit slip and the individual can either copy the information or can simply authorize the transaction. Individuals who cannot sign their name may use a sign or a name stamp. Balancing the account—which can be done by a friend or with the aid of a pocket calculator—can be completed at the time of the transaction or at some later time.

ITEM 2-4-2 Using a Checking Account

a. Making deposits
b. Making withdrawals
c. Writing checks

Maintaining a savings account is an ideal way to prepare for a rainy day.

After some initial assistance in opening the account, the rest is easy.

Making a deposit includes:

- Gathering necessary materials (bank book, money or check to be deposited, etc.)
- Traveling to bank
- Completing deposit slip
- Submitting deposit slip and money/check to teller
- Balancing account
- Continuing to next activity

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Caring for dirty clothing items will be structured by the larger household routine. Individuals may be asked to put dirty clothes in a laundry bag in their own room or to deposit them in a central hamper in the bathroom or a laundry area.

The material and equipment requirements of this activity will depend on the particular elements selected. There is a tremendous range in product packaging and equipment style that may affect individual performance, so consider options carefully before making a choice.

A picture self-monitoring system is helpful in defining the elements of the morning routine and sequencing them for logical completion.

ITEM 2-1-6 **Completing Morning Routine**

a. Brushing teeth
b. Using deodorant/anti-perspirant
c. Shaving
d. Taking a bath
e. Taking a shower
f. Washing face and hands
g. Washing hair
h. Blow drying hair
j. Flossing
i. Using rollers/curling iron/etc.
k. Using mouthwash
l. Using cologne/perfume/powder
m. Using makeup
n. Shaving legs and underarms
o. Caring for dirty clothing

Note: This activity may be coordinated with ITEM 2-3-1: Purchasing Personal Items. The planning team should review this activity and ITEM 2-1-7: Completing Evening Routine to ensure that all necessary personal hygiene elements are included in one activity or the other.

As each day begins, so it must end.

There is a tremendous variation in evening routine. Choose elements that were not included in the morning routine or those that make sense to repeat because of preference or personal hygiene needs.

Use picture self-monitoring cards to define and structure the routine.

ITEM 2-1-7 **Completing Evening Routine may include:**

a. Brushing teeth
b. Using deodorant/antiperspirant
c. Taking a bath
d. Taking a shower
e. Washing hair
f. Blow drying hair
g. Flossing
h. Using rollers/curling iron/etc.
i. Shaving legs and underarms
j. Caring for dirty clothing

Good Simulations

Simulations—training in a situation that is not the natural environment—can be used to provide extra practice on difficult steps of an activity or to provide more control for a trainer than would be possible in the natural setting itself.

The effectiveness of a simulation should always be judged by how well it improves performance in the natural environment.

Good simulations: 1) incorporate the same stimuli that should control behavior in the natural environment, 2) have the person practice a response that is similar in form to the response required in the natural setting, and 3) are always combined with training in at least one natural setting.

For more information about designing simulations, see:

Albin, R. W., McDonnell, J. J., & Wilcox, B. (1987). Designing interventions to meet activity goals. In B. Wilcox & G. T. Bellamy, *A comprehensive guide to The Activities Catalog: An alternative curriculum for youth and adults with severe disabilities* (pp. 63–88). Baltimore: Paul H. Brookes Publishing Co.

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IV. Evaluations & Forms

- Peer Buddy Class Schedule Form
- Record of Peer Buddy Experiences
- Peer Buddy Evaluation Form
- Peer Buddy Observation Schedule

PEER BUDDY CLASS SCHEDULE

Name: _____

Fall Semester

Clubs: _____ Meeting time: _____

_____ _____

PLEASE INCLUDE THE COURSE, TEACHER AND ROOM NUMBER (IF POSSIBLE)

	Monday	Tuesday	Wednesday	Thursday	Friday
1					
2					
3					
4					
5					
6					

Spring Semester

Clubs: _____ Meeting time: _____

_____ _____

	Monday	Tuesday	Wednesday	Thursday	Friday
1					
2					
3					
4					
5					
6					

PEER TUTORING PEERBUDD Y/PERBUDCL SCH

RECORD OF PEER BUDDY EXPERIENCES

As part of the course requirements, you are expected to complete a daily journal regarding your experiences as a peer buddy.

Completing Your Log:

In your daily log you may want to include your feelings, what you did with your special education partner, behavioral observations of your partner, what you enjoyed, what you did not enjoy, or any other important or relevant information.

Sample:

Date: 1/10/94
Activity: Went to the library
Reflections: Today, Sarah and I went to the library to check out books. It took us a while to get there because Sarah kept stopping and talking to people in the hallway. Sarah seemed to enjoy being in the library looking at the magazines. She smiled and laughed while we looked through them. I am starting to feel more comfortable with Sarah and had a fun day today.

RECORD OF PEER BUDDY EXPERIENCES

Peer Buddy _____ Study Partner_____

A daily record of your hours, activities, and reflections of experiences.

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Peer Buddy Observation and Evaluation Form

Peer Buddy:_____ **Partner:**_____

Teacher:_____ **Date:**_____

	Always	Often	Sometimes	Seldom	Never
A. Peer Buddy Characteristics:					
1. Dependable and helpful	5	4	3	2	1
2. Shows positive attitude	5	4	3	2	1
3. Starts on time	5	4	3	2	1
4. Uses time wisely	5	4	3	2	1
5. Completes assignments	5	4	3	2	1
6. Initiates activities independently	5	4	3	2	1
7. Has good rapport with partner	5	4	3	2	1
8. Uses reinforcement effectively	5	4	3	2	1
9. Seeks help if needed	5	4	3	2	1
10. Has completed assignments in manual	5	4	3	2	1

B. Activity and instructional and/or motivational strategies used:

C. Teacher recommendations:

D. Additional Comments:

_____ _____

Teacher Peer Buddy

Evaluation reviewed together on:_____
Date

Peer Buddy Observation Schedule

Peer Buddy/Period	Observations Dates/Comments	Evaluation & Feedback Sessions Dates/Comments

V. Introduction to Special Education Services

- Current Trends in Special Education
- Special Education Legislation & Definitions
  - Least Restrictive Environment
  - Multidisciplinary Team
  - Individualized Education Program
- Misconceptions about Exceptional Children
- Misconceptions about Persons with Disabilities
- County Graduates Defy Odds to Realize Goals
- Issues in Special Education: An Act of Transformation
- Peer Group Education

CURRENT TRENDS AND ISSUES

Bob Dylan could have written his song "The Times They are A-Changin'" for the field of special education. Special education has a rich history of controversy and change. In fact, controversy and change are what make the teaching and study of people with disabilities so challenging and exciting. The 1980's and 1990's have seen especially dramatic changes in the education of people with disabilities, and current thinking indicates that the field is poised for still more changes.

Integration

Integration, sometimes referred to as mainstreaming, involves the movement of people with disabilities from institutions to community living, from special schools to regular public schools, from special classes to regular classes. As a broadly supported social issue, integration began in the 1960's and is going stronger than ever today. In the 1960's and 1970's, champions of integration were proud of the fact that they were able to reduce the number of people with disabilities residing in institutions and the number of special education students attending special schools and special self-contained classes. Some of today's more radical proponents of integration, however, will not be satisfied until virtually all institutions, special schools, and special classes are eliminated. They propose that all students with disabilities be educated in regular classes. And even today's more conservative advocates of integration are recommending a much greater degree of interaction between students with and without disabilities that was ever dreamed of by most special educators in the 1960's and 1970's.

Normalization

A philosophical belief in special education that every individual, including those with the most severe disabilities, should have an educational and living environment as close to normal as possible.

Adapted from Exceptional Children: Introduction to Special Education, Hallahan and Kauffman.

SPECIAL EDUCATION LEGISLATION AND DEFINITIONS

Two landmark federal laws were passed in 1990: the Individuals with Disabilities Education Act (IDEA) and Americans with Disabilities Act (ADA). IDEA amended a 1975 law and it ensures that all children and youth with disabilities have the right to a free appropriate public education. ADA ensures individuals to non discriminatory treatment in other aspects of life and provides civil rights protection in areas of employment, transportation, public accommodations, and telecommunications.

IDEA legislation mandates that special education services be provided. Special education services are provided at no cost to parents, are designed to meet the unique needs of the child, and are supervised and directed by public school personnel in a setting that meets state standards. This is called a FREE APPROPRIATE PUBLIC EDUCATION (FAPE).

WHAT?

SPECIAL EDUCATION SERVICES	RELATED SERVICES	INDIVIDUALIZED EDUCATION PROGRAM
Special Education services are specially designed instruction determined by the unique needs of the student and should be as nearly like the regular school program as possible. Special Education can take place in a variety of settings from the regular classroom to hospital or home instruction.	Related Services are provided to assist the student to benefit from special education. Related Services include, but are not limited to, the following: • Transportation • Hearing Services • Vision Services • Counseling Services • Physical Therapy • Occupational Therapy • Speech/Language Therapy	All services must be provided according to an individualized education program or IEP. An IEP is a written program developed by the parents and the school system personnel and includes: • The type of services • Long-term goals for the student • Short-term objectives or intermediate steps; not daily lesson plans • Other services, if needed

Adapted from Step by Step, A Guide for Parents, TN Dept. of Education, Special Education Division.

PLACEMENT MUST OCCUR IN THE LEAST RESTRICTIVE ENVIRONMENT

The special education and related services to be provided and the amount of participation in the regular education program is called PLACEMENT. Placement must be provided in the LEAST RESTRICTIVE ENVIRONMENT. The Least Restrictive Environment is determined by the amount of time an eligible child spends with children who do not have disabilities.

WHERE?

LEAST	RESTRICTIVE	ENVIRONMENT
Students should attend the schools they would attend if they did not have a disability. If this is not appropriate, the place where student goes to school should be as much like the regular school and as close to student's home as possible.	The place where student goes to school should not separate him/her from the regular school program or from peers of similar chronological age any more than necessary.	Student's school program should be in a setting where he/she can be with non-disabled children as much as possible.

Adapted from Step by Step, A Guide for Parents, TN Dept. of Education, Special Education Division.

Decisions about the student's Individualized Education Program (IEP) in the least restrictive environment must be developed at a meeting of the MULTIDISCIPLINARY TEAM (M-TEAM).

WHO?

MULTIDISCIPLINARY TEAM

An M-Team is a group of people that mush include at least:

- the parent or legal guardian
- the student, when appropriate
- A teacher who knows about the instructional needs of the child
- The principal or someone that he/she assigns
- A specialist who understands and can explain the results of the student's assessment (this person is only required at the initial or first meeting)

The parent, or the school system may invite other persons to attend the M-Team meeting.

FOUR VERY IMPORTANT THINGS HAPPEN AT M-TEAM MEETINGS:

The members of the M-Team will do the following:

1. Determine if student is eligible for special education services at the time of the initial and re-evaluation (at least every three years),
2. Develop the individualized education program for the student,
3. Decide which special education services the student will receive, and
4. Decide if other services are essential to the educational program of the student.

Adapted from Step by Step, A Guide for Parents, TN Dept. of Education, Special Education Division.

THE INDIVIDUALIZED EDUCATION PROGRAM (IEP)

Contents of the IEP

When the M-Team meets to develop the IEP they will discuss the following components which will be included in the IEP:

(1) Student's present levels of performance;

(2) Annual goals expected to be achieved at the end of one year for area(s) of need;

(3) Short term objectives which measure progress toward meeting the goal(s);

(4) Specific educational and related services needed;

(5) A description of the amount of time, number of sessions, anticipated duration of the service, the date the service will begin and end, and who will be responsible for providing the service;

(6) The type of vocational services needed and, if they aren't needed, why such services aren't needed;

(7) A statement of the needed transition services for student beginning at age 16 (14 or younger, if needed) which will promote the understanding of and capability to make the transition from "student" to "adult";

(8) How much time the student will participate in regular education and in special education services provided in the regular classroom;

(9) State mandated tests which the child will take during the IEP period and, if appropriate, modifications to be made and

(10) Methods of monitoring the student's progress at least annually, and naming the person responsible for this monitoring.

After the M-Team has completed the IEP, the parent may request a copy of the IEP to take home.

NOTE: Some children with disabilities may need special equipment such as wheelchairs, braces, crutches or assistive technology devices/equipment. The school system must make arrangement, if required, in order for a child with a disability to attend and participate in school. Any necessary special arrangements should be included in the child's IEP.

Adapted from Step by Step, A Guide for Parents, TN Dept. of Education, Special Education Division.

MISCONCEPTIONS ABOUT EXCEPTIONAL CHILDREN

MYTH > Public schools may choose not to provide education for some students.

FACT > Federal legislation specifies that to receive federal funds, every school system must provide a free, appropriate education for every student regardless of any disabling condition.

MYTH > By law, the student with a disability must be placed in the least restrictive environment (LRE). The LRE is always the regular classroom.

FACT > The law does require the student with a disability to be placed in the LRE. However, the LRE is *not* always the regular classroom. What the LRE does mean is that the student shall be segregated as little as possible from home, family, community, and the regular class setting while appropriate education is provided. In many, but not all, instances this will mean placement in the regular classroom.

MYTH > The causes of most disabilities are known, but little is known about how to help individuals overcome or compensate for their disabilities.

FACT > In most cases, the causes of disabilities are not known, although progress is being made in pinpointing why many disabilities occur. More is known about the treatment of most disabilities than about their causes.

MYTH > People with disabilities are just like everyone else.

FACT > First, no two people are exactly alike. People with disabilities, just like everyone else, are unique individuals. Most of their abilities are much like those of the "average" person who is not considered to have a disability. Nevertheless, a disability is a characteristic not shared by most people. It is important that disabilities be recognized for what they are, but individuals with disabilities must be seen as having many abilities—other characteristics that they share with the majority of people.

MYTH > A disability is a handicap.

FACT > A disability is an inability to do something, the lack of a specific capacity. A handicap, on the other hand, is a disadvantage that is imposed on an individual. A disability may or may not be a handicap, depending on the circumstances. For example, inability to walk is not a handicap in learning to read, but it can be a handicap in getting into the stands at a ball game. Sometimes handicaps are needlessly imposed on people with disabilities. For example, a student who cannot write with a pen but can use a typewriter or word processor would be needlessly handicapped without such equipment.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 5.

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MISCONCEPTIONS ABOUT PERSONS WITH DISABILITIES

MYTH > Normalization, the philosophical principle that dictates that the means and ends of education for students with disabilities should be as culturally normative as possible, is a straightforward concept with little room for interpretation.	**FACT** > There are many disagreements pertaining to the interpretation of the normalization principle. As just one example, some have interpreted it to mean that all people with disabilities must be educated in regular classes, whereas others maintain that a continuum of services (residential schools, special schools, special classes, resource rooms, regular classes) should remain as options.
MYTH > All professionals agree that technology should be used to its fullest to aid people with disabilities.	**FACT** > There are some who believe that technology should be used cautiously because it can lead people with disabilities to become too dependent on it. Some believe that people with disabilities can be tempted to rely on technology rather than develop their own abilities.
MYTH > Research has established beyond a doubt that special classes are ineffective and that mainstreaming is effective.	**FACT** > Research comparing special versus mainstream placement has been inconclusive because most of these studies have been methodologically flawed. Researchers are now focusing on finding ways of making mainstreaming work more effectively.
MYTH > Professionals agree that labeling people with disabilities (e.g., retarded, blind, behavior disordered) is more harmful than helpful.	**FACT** > Some professionals maintain that labels help professionals communicate, explain the atypical behavior of some people with disabilities to the public, and spotlight the special needs of people with disabilities for the general public.
MYTH > People with disabilities are pleased with the way the media portrays people with disabilities, especially when they depict extraordinary achievements of such persons.	**FACT** > Some disability rights advocates are disturbed with what they believe are too frequent overly negative *and* overly positive portrayals in the media.
MYTH > Everyone agrees that teachers in early intervention programs need to assess parents as well as their children.	**FACT** > Some authorities are now of the opinion that, although families are an important part of intervention programming and should be involved in some way, special educators should center their assessment efforts primarily on the child and not the parents.
MYTH > Everyone agrees that good early childhood programming for students with disabilities should follow the same guidelines as that for nondisabled preschoolers.	**FACT** > There is considerable disagreement about whether early intervention programming for children with disabilities should be child-directed, as is typical of regular preschool programs, or should be more teacher-directed.
MYTH > Professionals agree that all students with disabilities in secondary school should be given a curriculum focused on vocational preparation.	**FACT** > Professionals are in conflict over how much vocational versus academic instruction students with mild disabilities should receive.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 47.

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OUNTY GRADUATES DEFY ODDS TO REALIZE GOALS > by Tammy Poole

PROGRESS PHOTO BY MATT GENTRY

Tony Hensley says he'd like to study business administration in college.

With a 3.8 grade-point average, Hensley is in the top 10 percent of his class.

Young photographer focuses on attending a more accessible UVa

The University of Virginia should be more accessible to Tony Hensley in a couple of years.

The problem is not academic. Right now, parts of UVa's campus are not physically accessible for the Western Albemarle High School senior.

Hensley was born with a muscular condition that left him weak, and he started using a wheelchair after he was injured in an automobile wreck.

"I plan to attend Peidmont Virginia Community College for two years and transfer to UVa," he said. "With the Americans with Disabilities Act, it should be more accessible in a couple of years."

In 1986, nine months after having two metal rods placed in his back to help correct curvature of the spine, Hensley was injured in a car accident.

He was trapped in the vehicle for 45 minutes, and his leg was broken in three places.

Being the only senior at WAHS in a wheelchair has not hindered his progress in any way, Hensley said.

The school is accessible for people with disabilities, he said. And his disability is no big deal to his classmates. He said he gets treated the same as everyone else.

He and his 215 classmates graduate tonight at 8 p.m. in Warrior Stadium at the High School.

With a 3.8 grade-point average, Hensley is in the top 10 percent of his class. He is a member of the National Honor Society and the French Honor Society and has won various academic awards. Hensley loves photography and stays busy photographing weddings and other events. He also was hired to photograph several senior portraits this year.

He became interested in photography while on the yearbook staff at Heritage Christian School.

Hensley drives a van and often goes on the Blue Ridge Parkway to take photographs that he mats and sells.

He is not sure whether photography would be profitable enough to make a living. "I'm interested in business administration," he said. "Eventually I'd like to be a business owner of some sort."

Hensley lives in North Garden with his parents, John M. and Betty Jo Hensley.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 8.

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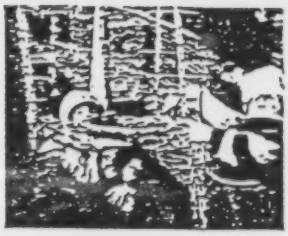
Issues in Special Education

An Act of Transformation: Law for Disabled to Change Workplace



CNN

The most far-reaching civil rights law since the 1960s takes effect Sunday, promising to force the kind of wholesale changes that would make the American workplace far more hospitable to workers with physical and mental disabilities.

The new law, the second phase of the Americans With Disabilities Act, outlines changes that companies must make to nearly every facet of employment, from job applications and interviews, to health insurance plans, compensation and work schedules—all designed to extend to the disabled the same rights that women and minorities won nearly three decades ago.

At many companies in the Washington area and across the country, managers already are bending and flexing to meet the needs of disabled workers.

Marriott Corp. uses interpreters to help a hearing-impaired employee at its Bethesda headquarters understand what is being said at staff meetings. A blind manager at Nordstrom's Pentagon City store has a scanner attached to his computer that reproduces ordinary documents in Braille.

In Atlantic City, owners of the Trump Castle casino altered a blackjack table to help a dealer who uses a wheelchair. And Continental Insurance, a New York-based property and casualty company, has an enlarging device attached to a computer so that a clerical worker with poor vision can see her keyboard more clearly.

Since it affects all industries, and ultimately touches millions of businesses, the act has a scope matched by few other laws. Generally, it is being praised by businesses as an effort to reach out to a disenfranchised segment of society. But it also has drawn criticism from industry groups that fear it could open the floodgates to litigation and subject businesses to large financial judgments by juries . . . .

The law does not state precisely what a company must do or spend to ensure that it does not discriminate, since what is appropriate for a commercial giant like IBM might not be for a small retailer. What the law does require is that employers make "reasonable accommodations" to assure that qualified applicants with physical or mental disabilities are not discriminated against, unless the employer can show that the accommodation would put an "undue hardship" on its operations.

For a large law firm, that could mean providing a reader for a lawyer who is blind; for a computer company, it could mean widening doorways or adjusting a desk's height to accommodate a systems analyst in a wheelchair.

The law goes well beyond traditional notions of disability by including any person with an impairment that substantially limits a major life activity. It protects people with AIDS, with cosmetic disfigurements, with dyslexia, even those who suffer from stress or depression if their condition is so severe as to be considered disabling by a psychiatrist . . . . To prepare themselves for the July 26 deadline, companies in recent weeks have been doing everything from scrutinizing the wording of job applications to reviewing hiring and promotion practices to ensure nothing they do could be considered discriminatory.

Under the new law, for example, applicants cannot be asked whether they have a disability, only whether they are able to perform specific functions that are considered essential to a job. For employers, that often means determining just exactly what are the essential functions of each job.

"Is it essential for a painter in a wheelchair to be able to reach the ceiling? Probably not, if we have a crew of 32 other painters who can do it," said Roger Wagner, president of Trump Castle, which is reviewing some 600 distinct jobs to determine their essential functions . . . .

Even with the force of the act on their side, many advocates for the disabled say it will be some time before the fortunes of that community improve significantly. The unemployment rate among those with disabilities is estimated to run as high as 60 percent and, as a result, many lack the skills necessary to compete for jobs.

"It is a Catch-22," said Peter Blanck, a University of Iowa law professor who is involved in a study of persons with disabilities. "If you haven't been in the work force, you won't have the skills needed for a lot of jobs."

The act does not mandate job quotas; it only requires that employers hire and promote qualified candidates, whether they have a disability or not.

To Mary Beth Chambers, a deaf employee who works the cosmetics counter at Nordstrom's Pentagon City store, the struggle for equality in the work place is well worth it.

"It's not people's fault that they're hearing-impaired," said Chambers, who reads customers' lips.

"Companies don't know what they're missing," she said. "These people are capable of doing anything, and if they keep trying, their dreams will come true."

SOURCE: Liz Spayd, *The Washington Post*, Sunday, July 26, 1992, pp. C1, C9. © 1992, The Washington Post. Reprinted with permission.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 31.

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Peer-Group Education

Although the widening world of childhood contains hundreds of lessons delivered by parents and teachers, young people deliver powerful lessons to one another, too. Small children are uncanny about teaching each other "the ropes" to acceptable childhood living. For example, I recall seven-year-old Bob McGee, with mental retardation and cerebral palsy, who fell to the floor kicking and screaming every time a teacher tried to take off his bib. Then when the developmental center closed down and Bob was transferred to a special class in a regular public school, he had attended for only two days before the bib came off! It takes little imagination to know what probably went on between him and the other students.

Teen-agers perform rich informal functions in teaching one another what life is all about and how they want their generation to shape the world. Although this curriculum cannot be found in books, teen-agers share with each other their own . . .

values
clothing styles
meaningful slang words
sense of justice
choice of foods
hope for the future
even their anger for mistakes their elders made before them.
(Have you forgotten?)

Until recently, many children with handicaps were denied peer-group interactions with others their own age. Like victims of apartheid, they attended special schools, rode special buses, and participated in special recreation programs. Of course, such distinctive activities had value, and there always will be a need for some specialized programs. Nevertheless, such utter isolation produced tragic consequences. It placed one more barrier in their path to the richest life possible. Now this unfair obstacle is being lowered.

Today many preschools integrate children with developmental disabilities into classes with their "normal" peers. And what often goes on in such settings can enlighten us all. A documentary film, *Why Be Friends*, described integrated preschools in eastern Nebraska. "Normal" children spoke openly and in unrehearsed fashion about their friends with handicaps. One four-year-old was asked about her relationship with a friend having multiple handicaps.

"What's that thing behind Carrie's head?"

"That's the thing that holds her head."

"Why does she have to have that?"

"Because then her head won't do anything, but it helps her lean back a lot."

"How would you feel if Carrie couldn't come here to school?"

"Well, then I'd go to her house."

Experiences like these in integrated preschools teach us that prejudice against persons with handicaps is *learned* behavior. And if prejudice can be taught by what we elders say (or fail to say), then tolerance, respect, and love for those with disabilities can be taught, too.

Forward-thinking public schools recognize the power of peer-group education. Dr. Lou Brown from the University of Wisconsin, which has close training relationships with the Madison Metropolitan School District, gave a touching rationale for such involvements at one of the symposiums on the United Nations' International Year of the Child (1979). He felt that neighborhood children should relate to students with even severe and profound handicapping conditions.

> Children with severe and profound handicaps need to be in regular schools, too. This interaction between these handicapped students and other students is utterly remarkable. And why not? After all, the future parents of such handicapped children are in the schools today. And what kind of

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attitudes, values and expectations will such parents need? Also, future doctors, teachers, lawyers, policemen and ministers are in the schools, too. They need to grow up with such children so they will understand them and not reject them. Therefore, we are making conscious and systematic attempts to make sure that every student has some kind of interaction with such handicapped people. And in some schools I work closely with, we train regular students to handle seizures in school . . . to work with handicapped students at recess, in the gym and the swimming pool . . . to hire out as baby sitters for handicapped children . . . to help some learn to ride the bus . . . to wheel students in wheelchairs to and from school. In many cases, regular students receive class credit for their involvements with handicapped persons. These students have become so attracted to one another, we can't keep them apart.[1]

Harold Howe II, the former United States Commissioner of Education and present vice president of Education and Research at the Ford Foundation, believes strongly that peer-group education will become a new way of life in public schools by A.D. 2024. He stated, "What the schools increasingly reward is not the student's own achievement but his contribution to the achievement of others. And the higher his own attainments in learning, the more he is expected to do in helping others to learn."[2]

It will happen. We can slow it down, however, as long as we keep people with handicaps apart from the rest of us.

Consider These Options

- Become interested in remarkable relationships between persons with handicaps and so-called normal persons in your neighborhood. They form the stuff books and speeches are made of. I make a living from such happenings—maybe you can observe relationships worth writing or talking about, too.

- Know that life becomes exciting and the world moves forward when people with individual differences understand and accept each other. After all, when we associate only with those who think like we do, act like we do, dress like we do, talk like we do—well, it can get downright boring.

- Watch your local public schools. Every time you see them develop a program that even smells like peer-group education involving persons with handicaps, reinforce them. Send written thank yous. Submit letters to editors. Thank the persons responsible personally. Even hug them and kiss them, if you can get away with it.

- Know that peer-group education is a coming way of life. It *is* coming. It is up to us to develop detailed responses that will help it along.

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1. Robert Perske, ed., *The Child with Retardation—The Adult of Tomorrow: An International Year of the Child Report Sponsored by the International League of Societies for the Mentally Handicapped and the Association for Retarded Citizens* (Arlington, Tex.: ARC-National Headquarters, 1980).
2. Harold Howe, "Report to the President of the United States from the Chairman of the White House Conference on Education, August 1, 2024," *Saturday Review World* (August 24, 1974).

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VI. Guidelines for Appropriate Language

- Talking about Disability
- Rules for Appropriate Language

This brochure is produced as a service of the Coalition for Tennesseans with Disabilities, an organization funded with grants from the Tennessee Developmental Disabilities Planning Council.

The Coalition is a statewide alliance of disability-related advocacy, planning, service provider, and professional organizations.

The Coalition's mission is to ensure that all adults and children with disabilities and their families have full access to integrated community-based services that reflect natural patterns of everyday living.

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Talking About Disability

A Guide to Using Appropriate Language

Times have changed for people with disabilities...

Life for most people with mental or physical disabilities is vastly improved over what it was twenty or thirty years ago.

Federal and state laws now assure that people with disabilities have the same basic rights as people without disabilities. Implementation of the Americans with Disabilities Act will further extend and guarantee these civil rights.

Some things have been slower to change; namely, attitudes and perceptions about people with disabilities. Ignorance and discrimination can be serious impediments to achieving integration, productivity, and independence for people with disabilities.

...but language lags behind

The use of outdated language and words to describe people with disabilities contributes greatly to perpetuating old stereotypes. No longer should we view people with disabilities as helpless or tragi victims.

Awareness is the first step toward correcting this injustice. If public opinion about people with disabilities is to be brought up to date, the public needs to he and learn to use appropriate language.

It is especially important for the media, elected officials, public speakers, and others in leadership positions to portray people with disabilities sensitively and realistically.

This brochure is intended as a guide to using descriptive words and language wh talking to or about people with disabilities

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Guidelines for Talking about Disability

1. Do not refer to a person's disability unless it is relevant.

2. Use "disability" rather than "handicap" to refer to a person's disability. It is okay to use "handicap" to describe accessibility accommodations, such as handicap parking; but it is better to use "accessible" in those instances. It is also okay to say that a person is handicapped by obstacles, such as architectural barriers or the attitudes of ignorant or insensitive people. Never use "cripple/crippled" in any reference to disability.

3. When referring to a person's disability, try to use "people first" language. In other words, it is better to say "person with a disability" or "man who has autism" rather than "a disabled person" or "an autistic man," particularly in a first reference.

4. Avoid referring to people with disabilities as "the disabled, the deaf, epileptics, the retarded, a quadraplegic," etc. Descriptive terms should be used as adjectives, not as nouns.

5. Avoid negative or sensational descriptions of a person's disability. Don't say "suffers from," "a victim of," or "afflicted with." Don't refer to people with disabilities as "patients" unless they are receiving treatment in a medical facility. Never say "invalid." These portrayals elicit unwanted sympathy, or worse, pity toward individuals with disabilities. Respect and acceptance is what people with disabilities would rather have.

6. Don't portray people with disabilities as overly courageous, brave, special, or superhuman. This implies that it is unusual for people with disabilities to have talents or skills.

7. Don't use "normal" to describe people who don't have disabilities. It is better to say "people without disabilities" or "typical," if necessary to make comparisons.

8. Never say "wheelchair-bound" or "confined to a wheelchair." People who use mobility or adaptive equipment are, if anything, afforded freedom and access that otherwise would be denied them.

9. Never assume that a person with a communication disorder (speech impediment, hearing loss, motor impairment) also has a cognitive disability, such as mental retardation. On the other hand, people with mental retardation oftentimes speak well.

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Rules for Appropriate Language

USE	AVOID
person with a disability / has a disability person with disabilities / have disabilities	*the* disabled / *the* handicapped invalids, patients crippled, deformed, defective (NEVER)
people without disabilities typical person non-disabled people (less preferred)	normal, healthy, able-bodied
wheelchair user / uses a wheelchair	wheelchair-bound / confined to a wheelchair
congenital disability / birth anomaly	birth *defect* / *affliction*
has cerebral palsy (CP) or other condition	a *victim* of cerebral palsy
has had polio / experienced polio has a disability as a result of polio	*suffers from* polio / *afflicted with* polio post-polios (as a noun referring to people)
people who have mental retardation (MR) person with mental retardation mentally retarded person (less preferred)	*the* mentally retarded / mentally deficient a retardate / a retard (NEVER) a feeble-minded person
child with a developmental delay (DD) person with a developmental disability	
person with Down Syndrome	the Down's person / Mongoloid (NEVER)
person who has epilepsy people with seizure disorders seizure / epileptic episode or event	*the* epileptic (to describe a person) *the* epileptics (to describe people) fits / epileptic fits
people who have mental illness person with a mental or emotional disorder	*the* mentally ill crazy, psycho, mental case (NEVER)
people who are blind / visually impaired person who is deaf / hearing impaired	*the* blind / blind as a bat (NEVER) *the* deaf / *the* hard of hearing deaf-mute / deaf and dumb (NEVER)
speech or communication disability	tongue-tied

VII. Task Analysis

- Task Analysis, What is it?
- Levels of Instructional Assistance

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TASK ANALYSIS

What is task analysis?

Task analysis is the process of breaking down a complex behavior into component parts. You determine what steps make up the task and in what order they must be performed.

Why do you do it?

It is the basis for teaching complex skills. It makes it easier to learn, to build from simple steps to the final complex behavior. It becomes easy to replicate.

How do you do it?

A. Pinpoint the terminal behavior. What is the skill or task you want to teach?

The scope of the main task should be limited. For example, the terminal behavior may be sharpening a pencil.

B. Observe someone performing the skill or perform it yourself.

C. List the necessary prerequisite skills; list the component skills in sequence.

Example:

1. Pick up a pencil with dulled point.
2. Insert correct end into sharpener.
3. Grasp handle of sharpener.
4. Rotate handle several times.
5. Remove pencil and check point for sharpness.
6. Reinsert pencil and repeat process if point is still dull.

On the following page is an example of a task analysis for writing a check. There is also a blank form to use in developing your own task analysis of a skill you want to teach.

HIS IS AN EXAMPLE OF ONE STUDENT'S TASK ANALYSIS FOR WRITING A HECK. EACH STUDENT'S TASK ANALYSIS MAY VARY.

Data Collection Sheet

ame_____

omain Community/Domestic/Leisure/Vocational

kill Write a check

KEY: + = Independent
V = Verbal Prompt
M = Modeled
- = Physical Assist

EVALUATOR	
DATE	

Task Analysis of Skill

. complete date - numerically
. complete "Pay To"
. write amount numerically
. write amount in words
. sign check
. record check number in register
. record date in register
. record payee in register
. record amount in register
0. subtract amount from balance

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Data Collection Sheet

Name_____

Domain_____

Skill_____

KEY: + = Independent
V = Verbal Prompt
M = Modeled
- = Physical Assist

EVALUATOR																														
DATE																														
Task Analysis of Skill																														

Levels of Instructional Assistance

You will decrease the level of assistance you give as your partner demonstrates competence on each skill or subskill.

1. **Verbal cue and physical assistance.** "Do it with me."

   You give a verbal direction and physically guide your partner through the entire task.

2. **Verbal cue and partial physical assistance.** "You do it."

   Give a verbal direction while directing your partner with small physical prompts.

3. **Verbal cue and model**. "Watch me."

   You model the behavior while giving the verbal direction.

4. **Verbal cue only.** "Listen carefully."

   You sit beside your partner and only give verbal directions.

5. **No assistance is necessary.**

   Your partner completes the task independently .

VIII. Dealing with Inappropriate Behavior

- How to Handle Inappropriate Displays of Affection
- Introduction to Behavior Management
- Your Teaching Session
- Principles of Behavior Management

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How to Handle Inappropriate Displays of Affection

It is important to remember that students with disabilities have the same feelings and urges as their fellow high school students. They watch the movies and television shows that demonstrate various ways affection is displayed. However, some students have not been given the opportunity to learn how to display their feelings appropriately. Therefore you, as a peer tutor, may need to help provide guidance and feedback as to what behavior is acceptable and what is unacceptable. Here are some suggestions:

* If you are ever in a situation in which you feel uncomfortable and are not sure how to handle it, bring it to the teacher's attention **immediately**.

* If a student is behaving in a way that makes you uncomfortable, it is best to address the problem directly. Feel free to tell the student that you are seeing someone or that you only want to be friends. Handle the situation as you would if the student did not have a disability. Ignoring the problem can send the wrong message and end up encouraging the student's affection.

* After directly addressing the behavior, redirection is the next thing to do. Direct the student's attention back to the task at hand. If the student is working, he/she can't be displaying the inappropriate behavior.

* Always inform the teacher of any situations that may arise. Often the teacher is already working with the student on displaying affection appropriately and can give you guidelines on how to handle the student's behavior.

Above all, you need to feel comfortable around the student. By addressing any behaviors that make you feel otherwise, you not only help improve your own peer tutoring experience, you will also help the student learn social skills that will help them throughout life.

Introduction to Behavior Management

This section will introduce you to the principles of behavior management. In particular, it will explain how to teach behaviors through reinforcement or reward. This is a very deliberate and systematic method of selecting a specific behavior which you want to influence or modify, and then developing a plan of reinforcement for doing it. You don't try to change the person. Rather, you change some of the individual's behaviors in a positive direction. The goal is individuals who can eventually reinforce themselves for their behavior through their own inner controls, individuals who are self-directed.

Using positive reinforcement to increase a desired behavior is not new or mysterious. We are all influenced by it. Here are some examples of where it is used:

1. It is used in business and industry where workers are reinforced, or rewarded for their efforts by increased salaries, promotions, incentives. These are the rewards that increase the worker's efforts to be more and more productive.

2. It is used in school where students are rewarded for their efforts by stars, grades, promotions, and their efforts are thereby reinforced.

3. It is used in grocery stores where buyers are reinforced for buying there on double coupon days.

Reinforcement: The basic tool for modifying or influencing behavior.

All behavior is learned, maintained, or changed by the consequences or effects of that behavior on the person. These consequences either reinforce (reward) that behavior or they fail to reward or reinforce that behavior.

How Reinforcement Works

1. Behavior that is reinforced tends to be repeated.

The behavior is strengthened. It is repeated because the consequences of that behavior have been rewarding or pleasing to the person and so he or she does it again in order to be pleased again by the consequences.

Example: Johnny comes home with a picture he has made in school. He shows it to his mother and she admires it (pleasing consequence). Johnny likes the admiration and he repeats his behavior of showing her what he has made.

2. Behavior that is not reinforced is not likely to be repeated. The behavior is weakened or eliminated.

It is not repeated because the consequences for the behavior have not been rewarding or pleasing. Thus, the individual finds no pay-off in repeating it. He or she "learns" that this behavior will get him nowhere.

Example: Johnny shows his mother the picture he has made in school, but she pays no attention to it. She ignores it (this consequence is not pleasing). Therefore, Johnny does not repeat the behavior of showing her what her has done in school because there was no pay-off for him for doing so.

Adapted from The Reinforcement Approach, Wittes and Radin

Principles of Behavior Management

This chapter includes excerpts from a manual teaching parents the principles of behavior management. It was designed to help them learn effective strategies to teach their children appropriate behaviors and decrease problem behaviors. It is a good introduction to the principles of behavior management which we all use and are all influenced by.

Following the parent guide is a review of the principles of behavior management and some worksheets to help you develop a behavioral program of your own.

This will give you some common strategies to use to encourage your partner to learn a new skill or to increase the use of a particular skill or behavior. It will also give you some strategies to use when you want to discourage or stop inappropriate behaviors.

Remember: You should first discuss any plans and concerns you may have with your supervising teacher and develop a behavioral intervention with his or her assistance and approval.

YOUR TEACHING SESSION

Before presenting specific speech and language skills to teach your child, we'll consider some general teaching strategies.

We'll emphasize *Regular Teaching Sessions* where you sit down with your child each day for 10-20 minutes to carry out a teaching program. You will learn the behavior modification method described in this manual best if at first you carry out Regular Teaching Sessions. Also, your child will benefit from Regular Teaching Sessions, especially when you are teaching a new skill.

We will also make suggestions throughout for how you can do *Incidental Teaching*—making use of teaching opportunities which arise during the day for *language stimulation.*

Read this section carefully, keeping your child in mind. First we will discuss strategies for presenting tasks to your child so that he will be likely to succeed. Then we will discuss how to reward his successes, so that he will enjoy learning and will want to try again.

To give you an idea of what a Regular Teaching session might be like, let's begin by looking in on Henry's speech lesson ....

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Excerpts from: Speech and Language, Baker, Brightman, Carroll, Heifetz, and Hinshaw.

One Teaching Session

It was two o'clock again, time for six-year-old Henry's speech lesson. Mrs. Griffin chose this time for their 20-minute practice session because Henry would have had time to unwind from his morning class, and the other children would not yet be home from school.

She quickly cleared the kitchen table and removed all of Henry's toys from the kitchen. She set up a chair for him, with its back to the room so that he was facing away from distractions. Then she brought Henry into the room. They began first with an exercise to teach Henry how to follow directions. This receptive language exercise was one of several programs in Mrs. Griffin's total teaching plan for Henry.

"OK, Henry, ready?"

Henry sat at the kitchen table next to his mother, eyeing the box of his favorite cheese-flavored crackers. The familiar routine started.

"Henry, look at me."

Henry looked at his mother.

"Good looking. Now, Henry, touch your nose."

Henry brushed his nose with his hand. "Right, Henry, good. You touched your nose. Have some cracker," and she dropped a piece into his open hand.

"Give me the spoon." "Good boy."

"Give me the spoon and touch your nose."

Henry hesitated, then touched his nose. "Listen, Henry. Give me the *spoon*, . . ." and his mother motioned toward the spoon, "and touch your *nose*," as she guided his hand toward his nose. "Good work," another bit of cracker.

Another Teaching Session was underway . . .

Setting the Stage

For a teaching session to go smoothly we have to plan ahead. Henry's mother carefully *set the stage for success,* by following these simple guidelines:

Plan short sessions

Plan a short teaching session, at least once a day. At first 5 minutes may be as long as your child can sit and pay attention. As he becomes accustomed to the teaching session, you can gradually increase the length of the session to 15 or 20 minutes.

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Be consistent

Try to have the teaching session at about the same time and in the same place every day so that your child will get used to the routine.

Minimize distractions

Choose a time and place to teach where distractions will be minimal. Choose a time, for example, when the other children are not competing for your attention. Choose a place which is relatively quiet and nondistracting—where toys, pets, or TV will not be in the way. Sit facing him, perhaps at a table or on a bed. Remember, in teaching speech, you *must* have his attention, so do your best to arrange your teaching session so that he will not be interested in something else.

Practice

Learning speech and language will be a difficult and slow process for your child. He will need to practice each step of each exercise many times. Keep an exercise consistent until he has mastered it and keep working on it for weeks—perhaps months.

Simplifying the Task

Henry's mother was also careful to *simplify the task* so that Henry could easily manage it without getting frustrated.

Planning

Plan the lesson in advance so that you know just what you are going to ask your child to do. Take a few minutes *before* the session to outline what you want to cover—it will make the lesson go much more smoothly.

Small steps

Gear teaching demands to what you know your child is able to do. Henry's mother had chosen one receptive skill area—following directions—and had chosen several exercises within that area. Then, rather than expect Henry to be able to master a two-part direction from the start, she had given him as much help as he needed. She began with the easier one-part direction and only later, as Henry became used to following directions, did she shift to the more difficult two-part direction. She would later gradually increase the difficulty of the task. *The most basic rule in behavior modification teaching is to proceed gradually to insure success.*

Instructions

Instruct your child in a clear, firm voice with no *wasted conversation* or unknown words to confuse him.

"HENRY, TOUCH YOUR NOSE."

Mrs. Griffin first got Henry's attention by using his name. Before starting the exercise, she made sure that he was watching and listening to her. Then her direction was simple and to the point. Instructions should use the same words each time. If you say "OK now, Henry, let's see if you can point up to your nose" one time and "Put your finger on your nose" the next, Henry will be lost. Keep directions *simple and consistent.*

Guiding

Take his hand, when necessary, and guide him through the movements you want. In this way your child can *see* very clearly what he is being asked to do, even though he may not initially understand what you are saying.

We will review these teaching principles throughout this manual. As you can see, they are all ways to simplify the task, to make it more manageable for your child so that he will succeed. When he does succeed, you will want to make sure you *reward* his efforts, so that he will be more likely to try again.

Rewards

When we stop to think of it, why should Henry, your child, or any retarded child want to try to learn anything? After all, learning has been very difficult for them. Their attempts to speak or understand language have not naturally led to the successes and smooth progress which other children experience. With a past history of such failures in learning, we can understand why they are not too eager to tackle a new learning task. In fact, they may strongly resist any new demand at all.

We have been talking about ways to arrange your child's world so that his failure and frustration in understanding and speaking are replaced by success. But just because you will be ready to teach him to follow directions or say new words does not mean that your child will be eager to learn. To him it may just look like another failure in the making.

You will need to find added incentives to draw him into the teaching session, to make him willing to try what you ask.

YOU WILL NEED REWARDS

Reward small steps

At first you will require that your child do just a little, like "touch your nose." If this is a new task, you may have to begin by physically guiding him to do it. When he succeeds (and he should, if you have properly set the stage), you will immediately praise him and give him a raisin, a sip of soda, or whatever other reward you have selected. Repeat that step several more times until he can do it easily, each time rewarding his success. Then, move on to the next step. Over time, your child will be able to do progressively more, receiving the reward at the end (and encouragement all along the way).

End with a success

If a given step in the task proves, after several attempts, to be too difficult, break the skill down still further, moving back to a slightly easier step. Each teaching session should begin with exercises already mastered, and then move on to new learning. Likewise, each teaching session should end with success. So, if he is getting restless, and it is getting near the time to stop, do *not* end right then. (You'll only be teaching him that if he gets fussy, he can end the session.) Rather, give a step you know he can do, and reward him for the success. Then, end the session.

Phase out rewards

As your child masters an exercise, you can phase out the extra rewards—the food and the activities. Praise alone will most likely support his performance and you can save the extra rewards for helping him with the steps of the next language exercise. Phase out rewards gradually by increasing the amount which you ask of him before giving one of the "extra" rewards. Eventually, the language skill will be a regular part of his behavior, and should be maintained by your praise and his increased mastery over his world. Remember, though, that your praise is *never* an "extra"; it should go with him whenever he is trying to learn or perform any skill.

In our example, Henry's mother has become a successful teacher of her retarded child because she follows these simple guidelines:

1. Plans the lesson in advance.
2. Sets the stage for success by minimizing distractions and practicing consistently.
3. Chooses a task that he is ready to learn.

4. Chooses rewards that he wants.
5. Simplifies the task by breaking it down into small steps and helping him through them.
6. Rewards all successes with praise, and new steps with special rewards.

Behavior Problems

Each child is unique and your child will no doubt have his own way of meeting a new teaching situation. However, we are certain about one thing: Your child will have some strategy for avoiding that teaching situation.

Perhaps he will cooperate until the first hint of failure, or perhaps you won't be even that lucky. Many children will show no interest in the task, will drop the materials, look everywhere but at you, or simply wander off. Others will fly into a rage at the first demand, with enough crying, biting, hitting, and screaming to make teaching seem hardly worthwhile. Some will be less obvious and will find cute things to do to distract you from teaching.

What you are seeing, partly, is a strategy for making a learning demand go away. In the past, every time these behaviors succeeded in making someone give up trying to teach they were strengthened a little bit.

We have seen that a desirable behavior, when followed by a reward, is more likely to happen again. *Well, an undesirable behavior (like screaming or looking away in the teaching situation), when followed by a reward (getting out of the teaching situation or receiving lots of attention), is more likely to happen again as well.*

Our emphasis is to minimize behavior problems by a teaching strategy which makes learning easy and fun. We have already talked about a number of ways to make success more likely for your child. Yet, despite your best efforts, problem behaviors will still happen.

We will mention just one specific guideline for now. If there are problem behaviors, ask yourself "Is the step too difficult or is she just trying to get out of it?" With practice you should be able to know when you have gone too fast and when you should expect a success.

What Is a Problem Behavior?

Your first task will be to decide exactly what is a problem behavior for your child. In the end, *you* must be the judge.

It may be that your child has obvious behavior problems, such as hitting, or screaming or running away. It may be that he bites his hands or scratches himself. Behaviors such as these are relatively easily defined as problems. On the other hand, your child may exhibit behaviors which pose problems in a more subtle way—crying when you leave him, wandering aimlessly, or rocking back and forth for hours.

It is often inappropriate behaviors such as these, rather than limited learning abilities, which lead others to view a

Excerpts from: Behavior Problems, Baker, Brightman, Heifetz, and Murphy.

special child as different and to react to him differently. At home, these behaviors further limit a child's opportunities to learn and they are a disruption to the household. In our experience, three types of behaviors are called problems:

Behaviors which interfere with learning

Eileen screams and hits whenever her parents try to teach her to identify pictures.

Eileen's acting up in teaching sessions is most apt to occur when she is asked to do something new. Her behavior makes it very difficult for her parents to work with her and, as a result, slows down her learning. "Acting-out" of this sort is one way a child's behavior says "No" to a learning situation, and the result is often that adults quit trying to teach.

Mike spends much of his time rocking from side to side.

Mike's rocking isolates him from other people and from materials in his world. By being absorbed in this behavior, he misses many opportunities to learn and do things throughout the day. Behaviors which limit a child's growth are not all of the dramatic, temper-tantrum variety; the child who rocks or wanders aimlessly, or sits absorbed with an object for long periods misses a great deal also.

Behaviors which interfere with skills already learned

Polly's mother has to stand over her and constantly urge her to dress herself.

Polly has learned to dress herself completely, but her stalling forces others to do things for her which she *can* and *should*

be doing on her own. Polly enjoys the attention she gets this way and her mother becomes especially annoyed; she knows Polly can dress herself.

Alison freezes at the top of a stairway, refusing to walk down alone.

If someone tries to get Alison to walk downstairs by herself, she pulls back, turns pale and screams; someone always ends up carrying her down.

Alison has a special type of problem behavior: she is afraid. Since a fall on the stairs many months ago, she has been terrified of walking down stairs, even though she is quite able to do this by herself.

Many children have fears like this; some children are afraid of water, or dogs, or darkness. Fears limit the opportunities a child has to learn new skills or to practice those already learned.

Behaviors which are disruptive to the family or harmful to the child

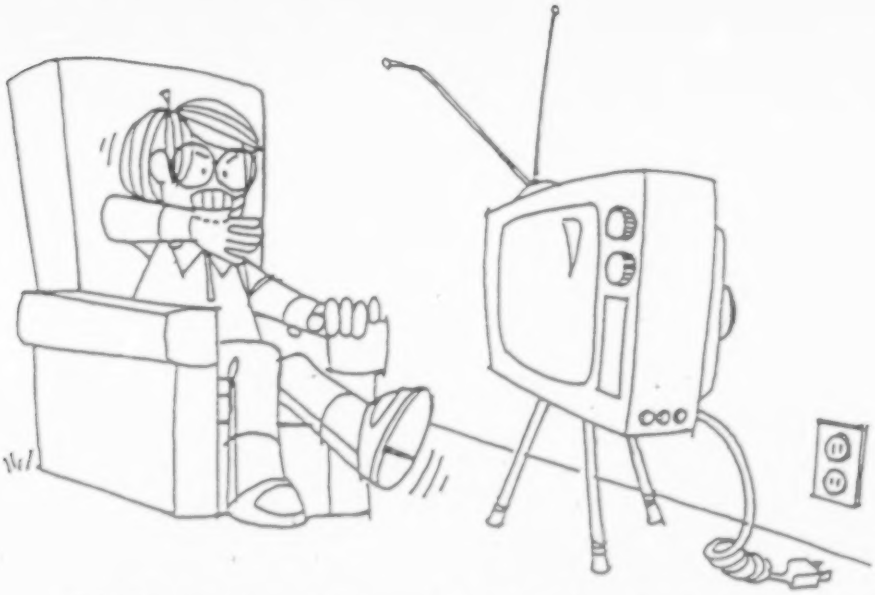
Jackie cries and screams every night at bedtime.

Jackie's crying and screaming at bedtime are very upsetting to the rest of her family. The other children are kept awake, and her parents have to spend much of their evening sitting up with her. It has reached the point where everyone dreads the bedtime struggle.

Behavior problems often lead families to make many adjustments from the way they would like to live.

Mark has temper tantrums; he screams and bites his hand.

Mark's self-abusive hand biting is especially upsetting to his family and dangerous to him. Hand biting is certainly painful and might well lead to permanent damage. More than almost any other behavior, self-abusive behavior is difficult to understand and upsetting to see.



Behavior is a powerful language indeed for a special child. And, as you can see from these examples, a great variety of behaviors can be problematic, because they:

1. Interfere with learning
2. Interfere with skills already learned
3. Are disruptive to the family or harmful to the child

Actually, most behavior problems fall into more than one of these categories. For example, Alison's fear of stairs both disrupts the family and prevents her from practicing a skill she has already learned.

No doubt you have read the above examples with your own child in mind, and it is likely you see his problems as fitting into one or more of these categories. We'll return to your child's behavior problems shortly. First, however, we want to introduce you to an essential aspect of the behavior modification approach—looking beyond the behavior to the context in which it takes place.

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PRINCIPLES OF BEHAVIOR MANAGEMENT

Motivating recipients to complete instructional programs and to change specific behaviors can be facilitated through the application of several basic behavioral management principles:

1. Find a set of reinforcers for the individual recipient

2. To increase a given behavior, follow that behavior **immediately** with a positive consequence. If a recipient is to accurately complete more tasks, he or she should be informed when he or she has been successful and should be provided with a positive consequence (i.e., the opportunity to engage in an activity which he or she enjoys) for accurate task completion. The positive consequence should be presented **immediately** if the recipient is expected to learn a new behavior.

3. State consequences positively. Inform the recipient that when he or she behaves in a specific way, a positive event will occur. This is in contrast to stating the negative (e.g., "If you do that again, I will take your radio away.") Unfortunately, with some recipients it may be necessary to present negative consequences to reduce a behavior. However, it is better to deal with behavior in a consistent, positive way, and all positive procedure should be tried first. If the instances of desired behavior are treated positively, the negative may not occur.

4. Avoid the use of punishment. Punishment has many potential side effects. It is hard to work with a learner who is trying to stay away from us or who is "fighting back".

5. Identify specific behaviors with which a recipient needs assistance. The primary emphasis should be placed on those behaviors which will lead to a recipient becoming more self-managing or controlling his or her problem behavior.

6. Record the frequency or duration of specific behaviors over selected periods of time. It is difficult to know what actually happens to a behavior if it is not recorded.

7. Be certain that the recipient can succeed. The recipient should be able to successfully perform the task given him or her.

8. Learning tasks should be developed around the interests of the recipient and should be taught in life settings (i.e., the places they will occur naturally). If possible, ask the learner what he or she would like to be able to do; tell the learner why he or she is completing a specific task.

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9. Select a task size that the recipient can reasonably complete. Both the size and the difficulty of each task should be considered. All of the steps in a given objective should probably not be taught at the same time.

10. Proceed in small steps, increasing the size and/or difficulty of the task.

11. After a recipient meets the criteria for success, immediately provide the reinforcement without adding additional requirements to it.

12. After the behavior reaches a desired level, provide reinforcement on an "occasional" basis.

13. The recipient should practice all skills in a variety of settings.

14. As a recipient proceeds on a task sequence, his or her progress should be monitored. If the individual is unable to perform a given task; (1) make certain that there is a positive consequence for mastering it; (2) re-evaluate the task size to be certain it is not too large; (3) re-evaluate the difficulty of the task to be sure the task and materials do not exceed the developmental skills of the individual.

GUIDE: PRINCIPLES OF BEHAVIOR MANAGEMENT

1. Reinforce desired behavior each time it occurs.
2. Reinforce desired behavior immediately.
3. State consequences positively.
4. Avoid direct punishment.
5. Identify individual reinforcers.
6. Select most natural reinforcers.
7. Record present status of behavior.
8. Involve the learner.
9. Increase task in small steps.
10. Follow through.
11. Be consistent.
12. Call for "life" application.
13. Reinforce established behavior intermittently.
14. Combine social consequences with arranged consequences.

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WHEN POSSIBLE, INVOLVE THE RECIPIENT IN BEHAVIOR-CHANGE DECISIONS

Review the guidelines below, and appraise your current practices. For example, ask, "Do we attend to inappropriate behavior more than we do the appropriate?" If so, discuss procedures for changing current practices and develop a planned approach.

GENERAL GUIDE

DON'T BECOME PREOCCUPIED WITH PROBLEM BEHAVIOR.

CATCH RECIPIENTS BEHAVING APPROPRIATELY AND REINFORCE THE BEHAVIOR.

AVOID ACCIDENTALLY STRENGTHENING UNDESIRED BEHAVIOR BY ATTENDING TO IT.

STRENGTHEN DESIRED ALTERNATIVE BEHAVIOR RATHER THAN ONLY REDUCING THE PROBLEM BEHAVIOR.

MAKE CERTAIN THAT BEHAVIOR CHANGE IS BENEFICIAL TO THE RECIPIENT.

TRY ALL POSITIVE APPROACHES BEFORE USING PUNISHMENT TO CHANGE BEHAVIOR.

AVOID CONVENIENCE MANAGEMENT——ASSURE COMMUNITY APPLICATION.

CONSIDER INDIVIDUAL DIFFERENCES.

BE CONSISTENT IN IMPLEMENTING PROGRAMS.

WHERE POSSIBLE, INVOLVE THE RECIPIENT IN THE BEHAVIOR-CHANGE DECISION.

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DESIGNING PROGRAMS FOR BEHAVIOR CHANGE

Dealing with problem behavior on a day-to-day basis without a program is likely to result in few changes. If many staff interact with a recipient, each of them may do different things. If we react to a behavior only when it bothers us and not at other times, the behavior is not likely to be managed effectively. We must plan ahead! While development of a systematic program requires planning in each area, the following steps must be considered:

1. Select a precise target behavior;
2. Assess the environment in which the behavior occurs;
3. Observe and record the behavior;
4. Prescribe your objectives;
5. Design a program for behavior change.

All that remains is to implement the program consistently, observe the effects, and modify where needed.

You have already stated the target behavior in precise terms. The next step is to assess the environment in which the behavior occurs.

SYSTEMS GUIDE

SELECTING A TARGET BEHAVIOR ——>

ANALYZING ENVIRONMENTS ——>

OBSERVING AND RECORDING BEHAVIOR ——>

PRESCRIBING OBJECTIVES ——>

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DESIGNING PROGRAMS FOR BEHAVIOR CHANGE

Henry's mother, you noticed, was prepared with his favorite cheese-flavored crackers. But a reward can be many things—anything your child enjoys or looks forward to! For the retarded child, as well as for ourselves, rewards are a payoff for a job well done.

To increase your child's speech and language skills, you will need to find what is rewarding for him. At first, succeeding at a task may not be half as rewarding as receiving a smile, hearing you praise him, or getting a taste of his favorite snack.

For the child learning language or any new skill, there are three types of rewards that often prove most effective:

1. Attention
2. Favorite snacks
3. Favorite activities

Your praise and attention

It may sound funny but the biggest reward you can offer your child is yourself, and you can do so in any number of ways: cheerful praise, smiles, hugs, tickles, bouncing him on your lap—whatever he likes most.

Favorite snacks

Whatever is a "treat" for your child will serve as a powerful reward in the learning situation: a favorite candy, bits of a cookie, cereal, ice cream, juice, apple, raisins. The list is endless and only you will know what is a rewarding snack for your child. Snack rewards in a speech session should be in small portions and easy to give. You can save larger rewards for the end of a session.

Favorite activities

Perhaps your child enjoys playing outside with dad, riding a tricycle, playing with blocks, or listening to the radio. Again, the possible list is endless. A short period of time playing with his brother or sister is often a good activity reward. Here, as before, you know your child and his interests best.

The reason for using these rewards in the teaching situation is a simple one:

BEHAVIORS FOLLOWED BY REWARDS ARE MUCH MORE LIKELY TO HAPPEN AGAIN.

Think about your child's likes and dislikes so that you can make a list of rewards to use when teaching him language exercises.

Below is a short list of items that may be rewards for your child.

Attention	*Food*	*Activity*
A smile	Juice	Playing catch
Saying "Good boy/girl"	Fruit	Playing outside
A hug	Dry cereal	Listening to music
Being tickled	Candy	Coloring with crayons

You must realize that none of these rewards is guaranteed to work with your child for the simple reason that we did not think of them with your child in mind. Only you can do this; only you know what might be especially rewarding *just* for him. Think of these and list them below.

Possible rewards:

Attention	*Food*	*Activity*

Please do not go further in the manual until you have written in possible rewards. Teaching language skills is a long and difficult task. Parents who succeed make the effort to write in the manual as they go along.

Rewards can be a very powerful tool in the hands of an effective teacher. But, as with most tools, they can sometimes be accidentally misused. As a result, instead of working for you they can very suddenly be working against you.

To make sure rewards are working *for* you, we ask that you pay close attention to the following points. Read, reread, and remember them: they are based on what we have found to be the most common problems with rewards among the parents we have worked with.

Make certain your rewards are rewarding

Favorite snacks are less effective rewards when used right after lunch. Fun toys are certainly less so when they've just been played with. Increase the effectiveness of whatever rewards you decide to use by seeing to it that your child will really want and look forward to them. If you cannot find another reward that he will work for, use his meal itself, giving small bites for successful performance of the task. Food will nearly always be an effective reward if your child is hungry. However, food may interfere with expressive language exercises, so if you do use food, give only very small amounts and make sure his mouth is empty before your next direction.

Give your reward as soon as the child performs the desired behavior

If you have to wait before finding and giving your child what he's earned, he may have forgotten what he did to earn it. Worse yet, in those two minutes he may perform other behaviors that you shouldn't be rewarding. So, when your child does what you asked of him, always praise him and *immediately* give him any other reward you are using.

Pay no attention to problem behaviors

We don't often think of our occasional yelling or getting up to chase a child around the room as rewards. Yet these are forms of *attention* to children. And attention, as we have seen, is a very effective reward. Remember the simple rule: Behaviors followed by rewards are much more likely to happen again. Save your attention for those behaviors that you want in the teaching situation. Let your child learn that if he wants your attention, he won't get it by running around the room or staring out of the window. As much as possible, remain seated and ignore these behaviors, waiting for him to turn his attention back to you. He should only get your attention by doing what is asked. If you must go to get him back, do *not* scold or criticize. Matter-of-factly take him back to his seat without giving him eye contact or any other attention. Give your attention only *after* the next *success.*

IX. Mental Retardation

- General Information about Mental Retardation (NICHCY Fact Sheet)
- Misconceptions about Persons with Mental Retardation
- The Importance of Friendship
- General Information about Down Syndrome (NICHCY Fact Sheet)
- Mainstreaming Case History: R.J. was Mentally Retarded
- Employment Case History: Love Story

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General Information About

MENTAL RETARDATION

Definition

People with mental retardation are those who develop at a below average rate and experience difficulty in learning and social adjustment. The regulations for the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (Public Law 94-142), provide the following technical definition for mental retardation:

> "Mental retardation means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational performance."

"General intellectual functioning" typically is measured by an intelligence test. Persons with mental retardation usually score 70 or below on such tests. "Adaptive behavior" refers to a person's adjustment to everyday life. Difficulties may occur in learning, communication, social, academic, vocational, and independent living skills.

Mental retardation is not a disease nor should it be confused with mental illness. Children with mental retardation become adults; they do not remain "eternal children." They do learn, but slowly and with difficulty.

Probably the greatest number of children with mental retardation have chromosome abnormalities. Other biological factors include (but are not limited to): asphyxia (lack of oxygen); blood incompatibilities between the mother and fetus; and maternal infections, such as rubella or herpes. Certain drugs have also been linked to problems in fetal development.

Incidence

Some studies suggest that approximately 1% of the general population has mental retardation (when both intelligence and adaptive behavior measures are used). According to data reported to the U.S. Department of Education by the states, in the 1989-90 school year, 564,666 students ages 6-21 were classified as having mental retardation and were provided services by the public schools. This figure represents approximately 1.7% of the total school enrollment for that year. It does not include students reported as having multiple handicaps or those in non-categorical special education preschool programs who may also have mental retardation.

Characteristics

Many authorities agree that people with mental retardation develop in the same way as people without mental retardation, but at a slower rate. Others suggest that persons with mental retardation have difficulties in particular areas of basic thinking and learning such as attention, perception, or memory. Depending on the extent of the impairment—mild, moderate, severe, or profound—individuals with mental retardation will develop differently in academic, social, and vocational skills.

Educational Implications

Persons with mental retardation have the capacity to learn, to develop, and to grow. The great majority of these citizens can become productive and full participants in society.

Appropriate educational services that begin in infancy and continue throughout the developmental period and beyond will enable children with mental retardation to develop to their fullest potential.

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As with all education, modifying instruction to meet individual needs is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

In teaching persons with mental retardation, it is important to:

- Use concrete materials that are interesting, age-appropriate, and relevant to the students;
- Present information and instructions in small, sequential steps and review each step frequently;
- Provide prompt and consistent feedback;
- Teach these children, whenever possible, in the same school they would attend if they did not have mental retardation;
- Teach tasks or skills that students will use frequently, in such a way that students can apply the tasks or skills in settings outside of school; and
- Remember that tasks that many people learn without instruction may need to be structured, or broken down into small steps or segments, with each step being carefully taught.

Children and adults with mental retardation need the same basic services that all people need for normal development. These include education, vocational preparation, health services, recreational opportunities, and many more. In addition, many persons with mental retardation need specialized services for special needs. Such services include diagnostic and evaluation centers; special early education opportunities, beginning with infant stimulation programs and continuing through preschool; and educational programs that include age-appropriate activities, functional academics, transition training, and opportunities for independent living and competitive employment to the maximum extent possible.

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Resources

Smith, R. (Ed.). (1993). *Children with mental retardation: A parents' guide.* Rockville, MD: Woodbine House. [Telephone: 800-843-7323 (outside DC area); (301) 468-8800 (in DC area).]

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life.* Rockville, MD: Woodbine House. (See telephone number above.)

Organizations

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003

American Association on Mental Retardation (AAMR)
1719 Kalorama Road, N.W.
Washington, D.C. 20009
(202) 387-1968; (1-800) 424-3688 (Toll-Free)

National Down Syndrome Congress
1605 Chantilly Drive Suite 250
Atlanta, GA 30324
(400) 633-1555; (1-800) 232-6372 (Toll-Free)

National Down Syndrome Society
666 Broadway, Suite 810
New York, NY 10012
(212) 460-9330; (1-800) 221-4602 (Toll-Free)

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UPDATE 12/93

MISCONCEPTIONS ABOUT PERSONS WITH MENTAL RETARDATION

MYTH > Mental retardation is defined by how a person scores on an IQ test.	FACT > The most commonly used definition specifies that, in order for a person to be considered mentally retarded, he or she must meet two criteria: (1) low intellectual functioning *and* (2) low adaptive skills.
MYTH > Once diagnosed as mentally retarded, a person remains within this classification for life.	FACT > A person's level of mental functioning does not necessarily remain stable, particularly for those who are mildly retarded. With intensive educational programming, some persons can improve to the point that they are no longer retarded.
MYTH > In most cases, we can identify the cause of retardation.	FACT > In most cases, especially of those who are mildly retarded or who require less intensive support, we cannot specify the cause. For many children who are mildly retarded, poor environment may be a causal factor, but it is extremely difficult to document.
MYTH > Most mentally retarded children look different from nondisabled children.	FACT > The majority of children with mental retardation are mildly retarded, or require less intensive support, and most of these look like nondisabled children.
MYTH > We can identify most cases of mental retardation in infancy.	FACT > Because most children with retardation are mildly retarded, because infant intelligence tests are not very reliable and valid, and because intellectual demands on the child increase greatly upon entrance to school, most children with retardation are not identified as retarded until they go to school.
MYTH > Persons with mental retardation tend to be gentle people who have an easy time making friends.	FACT > Because of a variety of behavioral characteristics and because they sometimes live and work in relatively isolated situations, some persons with mental retardation have difficulty making and holding friends.
MYTH > The teaching of vocational skills to students with retardation is best reserved for secondary school and beyond.	FACT > Many authorities now believe it appropriate to introduce vocational content in elementary school to students with mental retardation.
MYTH > When workers with mental retardation fail on the job, it is usually because they do not have adequate job skills.	FACT > When they fail on the job, it is more often because of poor job responsibility (poor attendance and lack of initiative) and social incompetence (interacting inappropriately with coworkers) than because of incompetence in task production.
MYTH > Persons with mental retardation should not be expected to work in the competitive job market.	FACT > More and more persons who are mentally retarded hold jobs in competitive employment. Many are helped through supportive employment situations in which a job coach helps them and their employer adapt to the work place.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 117.

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THE IMPORTANCE OF FRIENDSHIP

Professionals often overlook the fundamental importance of friendship. The following extract highlights the critical role friendship can play in the lives of people who are mentally retarded.

> A sense of belonging, of feeling accepted and of having personal worth are qualities that friendship brings to a person. Friendship creates an alliance and a sense of security. It is a vital human connection.
>
> People who are mentally retarded want and need friendship like everyone else. Yet they typically have few opportunities to form relationships or to develop the skills necessary to interact socially with others. Their exposure to peers may be limited because they live and work in sheltered or isolated environments. They usually lack a history of socializing events like school clubs, parties, or sleepovers that help to develop or refine personal skills. They may not know how to give of themselves to other people and may be stuck in an egocentric perspective. Persons who are retarded may also respond inappropriately in social situations. Many people shun adults with retardation who freely hug or kiss strangers when greeting them . . . .
>
> Because of their few contacts and opportunities, persons with retardation may attempt to befriend strangers or unwitting individuals. Many attempt to become social acquaintances with their professional contacts. In their effort to maintain the contacts and relationships they have developed, some individuals will overcompensate: calling their friend too many times, talking too long on the phone, demanding attention, and not being able to let up . . . .
>
> Friends can play a vital role in the adjustment to community living of adults who are retarded by providing the emotional support and guidance through the exigencies of daily life. Certain organizations have begun to address the need for friendship by initiating social opportunities . . . [There are] social club[s] for adults with retardation in which members plan their own parties and projects. Some programs offer supervised dating; others establish one-to-one relationships between volunteers and clients for the purpose of aiding adjustment. (Patton, Payne, & Beirne-Smith, 1990)
>
> With the increase in mainstreaming, many hope the problems that numerous persons with mental retardation have in obtaining and holding friendships will decrease. In the future, it will be interesting to see to what degree professionals will organize social clubs exclusively for persons with mental retardation versus having them socialize with nondisabled persons

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Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 138.

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General Information About

DOWN SYNDROME

Definition

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

Incidence

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

Characteristics

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears;
- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a tendency to become obese as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

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Educational and Employment Implications

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has proven successful. Improved public acceptance of persons with disabilities, along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group-shared and supervised apartments, and support services in the community have proven to be important resources for persons with disabilities.

Resources

Brill, M.T. (1993). *Keys to parenting a child with Down syndrome.*. Hauppauge, NY: Barron's.

National Down Syndrome Congress. (1988). *Down syndrome* (revised pamphlet). (See address below.)

Pueschel, S.M. (Ed.). (1990). *A parent's guide to Down syndrome: Toward a brighter future.* Baltimore, MD: Paul H. Brookes. (Telephone: 1-800-638-3775.)

Stray-Gundersen, K. (1986). *Babies with Down syndrome: A new parent's guide.* Rockville, MD: Woodbine House: [Call Woodbine House at 1-800-843-7323 (outside DC area) or (301) 468-8800 (in DC area).]

National Down Syndrome Society. *This baby needs you even more.* (See address below.)

Organizations

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(404) 633-1555
(800) 232-6372 (Toll Free)

National Down Syndrome Society
666 Broadway
Suite 810
New York, NY 10012
(212) 460-9330
(1-800) 221-4602 (Toll Free)

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003; 1-800-433-5255

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MAINSTREAMING

CASE HISTORY

R. J. WAS MENTALLY RETARDED

BY MARY DEAN BARRINGER

As a 2nd grader, R. J. made numerous speech errors during oral reading and conversation. His teachers tried a variety of approaches to help him learn to read, but with little success. R. J. also needed step-by-step guidance to do simple seatwork. These problems, coupled with R. J.'s difficulties in auditory memory, prompted his 3rd-grade teacher, Chris Kramer, to suggest IQ testing. After some resistance, R. J.'s parents agreed to the testing, which confirmed that R. J. was educably mentally impaired.

OUR FIRST STEP WAS TO REASsure R. J.'s parents. My principal and I met with them and told them that the test results would guide us in making good, informed decisions about R. J.'s education. We assured them that we'd work with R. J. so he could go on to 4th grade with his friends. And they volunteered to be a tutor for R. J. and to help him with his homework each night.

Then, feeling that "less is more" was an appropriate guideline for a student like R. J., I concentrated on developing his basic math and language skills. Because language processing was difficult for R. J., I supplemented all oral directions with gestures or written cues. Not only did this benefit R. J., but my other students seemed to attend to directions more effectively as well. I'd also cue R. J.'s oral responses with open-ended sentences that helped him retrieve words, using sentence patterns such as "You saw the..." or "You liked the..." Visual reminders, such as an index card on his desk reminding him to put his name on each paper, helped him increase his independence as well as his ability to handle simple memory requirements.

Because R. J. was unsure of his own abilities, he tended to attach himself to one peer and imitate his work. But by eliciting R. J.'s own preferences, intentions, and interests, I helped him see himself as a valued class member with his own point of view. For example, I'd ask such questions as "R. J., do you have a favorite _____?" or "What do you think, R. J.?" I also assigned R. J. to a cooperative learning group that could work under my guidance to help him.

With the additional support of a speech therapist, who worked with him regularly on his language problems, and the tutoring provided by his parents, R. J. improved dramatically. By the end of the year, although not reading at grade level, he'd made enough progress to keep up with classmates and he was better able to do independent seatwork.

R. J.'s future success would depend on ongoing assessment and communication among the school's professionals and his parents. At the end of the year, with all the support techniques set up to continue, I confidently promoted him to 4th grade.

Resources

The Council for Exceptional Children, 1920 Association Dr., Reston, VA 22091, has information on educating children with exceptional needs.

Mary Dean Barringer, a former special education teacher, is currently the director of programs for the advancement of teaching for the National Board for Professional Teaching Standards.

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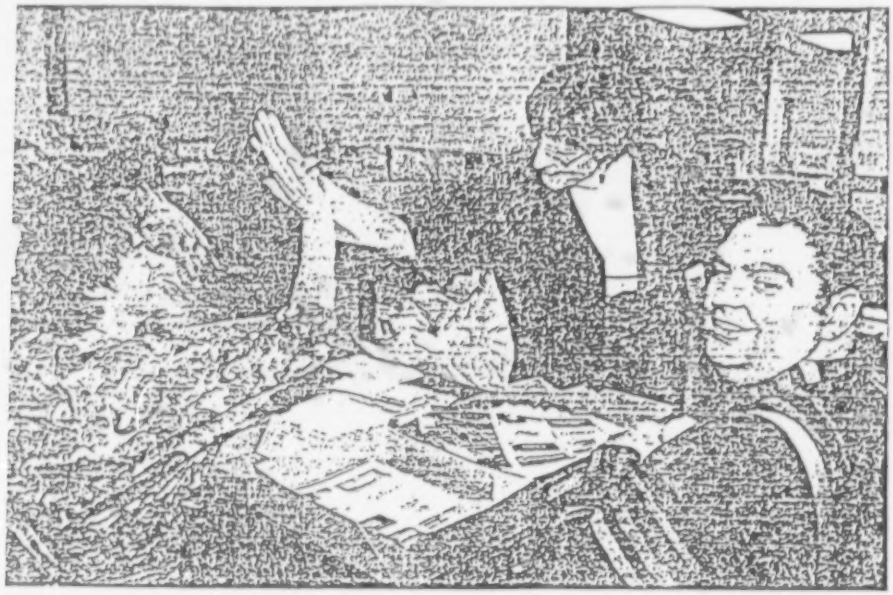
ANGELS

LOVE STORY

Seeking work for a Down syndrome child, the Roys didn't stop at a job—they created a company



LIKE EMPLOYEES IN MANY CLOSE-KNIT COMPANIES, the labelers, staplers and collators of the Special Persons Mailing Service in Virginia Beach, Va., trade gossip, celebrate each other's birthdays and go out together after work on Friday. But they sometimes need a little extra help. There's the young woman who never can remember which day of the week is payday. There's the employee who asks the boss for help in buckling his belt after a trip to the bathroom. And, from time to time, a seizure will disrupt the quiet office routine. Two things distinguish the employees at Special Persons: They are all mentally handicapped—many with Down syndrome—and they are unusually devoted to their jobs. "A lot of outfits would like to have people with their work habits," says Art Roy, who, with his wife, Floy, founded the company four years ago. "I don't think you could chase them out of here."

Special Persons arose from the Roys' desire to see their own Down syndrome daughter, Jennifer, 23, secure a place in the world. It has wound up providing a haven—and a small paycheck—for 21 others. And it has managed to survive, even to edge slightly into the black, without a penny of government subsidy.

In 1991, Jennifer, the youngest of the Roys' three children, started looking ahead to graduation from Princess Anne High School, a public school where she had received intensive special education. "I could just see the handwriting on the wall," says her mother, Floy, 61, a bookkeeper for a Roman Catholic parish. She had seen what happened to other handicapped people when they finished school: "All of a sudden they had no place to go; their lives were at a standstill. Yet I felt they had a lot they could offer the community."

The Roys have been fighting for their daughter since she was born. At the time, recalls Art, 67, "everybody said, 'Don't take her home. She's not going to have a normal life.' " But the Roys, convinced that putting people with Down syndrome in institutions tends to shorten their lives, did take Jennifer home to join their sons Norman, now 42, and Gary, 36. "She has al-

▲ Mailing company employees like Ray Clark and Kay Loper (high-fiving training coordinator Colleen Dam Weber, in glasses) "don't like to stay at home—even if they're sick," says Floy.

➤ With their two sons grown, says Floy Roy (with husband Art, daughter Jennifer and Heidi the schnauzer), "we have to fight for Jennifer and make a life for her."

Photographs by Robin Bowman

5/15/95 People

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ways been a joy and the focus of our lives—it's been a happy time," says Art. "Down syndrome children are real loving; they teach you a lot about patience, love and understanding."

As Jennifer's graduation approached, Floy had an inspiration. Her church, St. Pius X, had piles of collection envelopes to be labeled and mailed. These were skills Jennifer had been taught in special ed, so Floy asked the pastor if he would allow Jennifer and four of her handicapped friends to pitch in as trial volunteers.

In March 1991, with Floy and Art supervising, Jennifer and crew set to work in the Roys' brick suburban home. Not only did they lick the job but their reliability soon brought them recommendations for similar jobs—all unpaid—for the Special Olympics, the ASPCA and the Boy Scouts. By June the

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operation had picked up enough steam to move into donated office space, and in September the Roys began billing clients at competitive rates and paying their growing roster of eager employees. While most of them are too profoundly handicapped to fully grasp the concept of money, says Art Roy, they enjoy their weekly trip to a local bank, where they deposit their wages and are fussed over by the tellers. "The amount in the pay envelopes isn't important," says Art, a former career Navy officer who spends what would have been his retirement managing the mailing service, "but it gives them a sense of doing something important."

Special Persons gets half its employees from Skill Quest, a Virginia Beach program that teaches job skills to handicapped people and pays the company a fee of $20 a day for each of its clients working there. Under an exemption from federal minimum-wage laws, the workers are paid an average of $3 an hour, with most taking home between $60 and $90 a week. At least one employee, Wanda Beasley, 29, who says labeling is her favorite thing about work, is saving her money. Her plans include summer camp and shopping. "I like to buy clothes," she says.

For the parents of the Special Persons work force—most of them retirees who volunteer one or two days a week and help with the more difficult tasks such as sorting by zip code—seeing their children off to work is an uplifting experience. Earlene Whittle, a retired special-ed teacher, says her Down syndrome daughter, Shari, 26, "would go to work seven days a week" if it were up to her. Word has gotten around. There is now a waiting list of prospective employees.

Corporate customers are delighted too. Nancy Walton, advertising manager for Checkered Flag Toyota, in Virginia Beach, found Special Persons in the Yellow Pages a year-and-a-half ago; she learned that its employees were disabled only after they had successfully completed their first job for her. Impressed, she has continued to hire them, sending about $19,000 worth of work their way last year. For Walton, as for other customers, there's an added benefit. "You get off the phone, and you say, 'Wow, I've done something good today,' " she says. "You need that every once in a while."

In fact, Special Persons is doing so well that, after vacating its donated space in September 1993 and moving to $550-a-month rented quarters, the company already is looking for a bigger place. "It just kind of mushroomed," says Floy, noting that the company finally turned a profit after about two years of operation. "I don't think we ever intended for it to be this big." Art, though, who doesn't draw any salary, is leery of too much financial success. "I sort of would like to keep it like a mom-and-pop grocery," he says, "where you have that atmosphere and attitude."

In a larger company, Heidi Wendt, 38, who spends her day stamping mailing permit numbers on flyers for the Toyota dealership, might not look at Art and say, "He's my sweet, lovable boss." And Art might not be able to shake his head and say, "Instead of one child, I feel I have about 20."

■ JENNIFER MENDELSOHN *in Virginia Beach*

A Schoolmate Larry Benhase, now a fellow worker at Special Persons, accompanied Jennifer to her senior prom at Virginia Beach's Princess Anne High School in 1993.

◄ Recognizing that he and Floy are getting older, Art (with employees Larry Benhase and Wanda Beasley) says they have set up a board of directors to keep Special Persons going after he and his wife are no longer involved.

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X. Learning Disabilities

- General Information about Learning Disabilities (NICHCY Fact Sheet)
- Misconceptions about Persons with Learning Disabilities
- "I Couldn't Read Until I was 18"

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free) (202) 416-0300 (Local, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

General Information About

LEARNING DISABILITIES

Definition

The regulations for Public Law (P.L.) 101-476, the Individuals with Disabilities Education Act (IDEA), formerly P.L. 94-142, the Education of the Handicapped Act (EHA), define a learning disability as a "disorder in one or more of the basic psychological processes involved in understanding or in using spoken or written language, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations."

The Federal definition further states that learning disabilities include "such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." According to the law, learning disabilities do not include learning problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural, or economic disadvantage. Definitions of learning disabilities also vary among states.

Having a single term to describe this category of children with disabilities reduces some of the confusion, but there are many conflicting theories about what causes learning disabilities and how many there are. The label "learning disabilities" is all-embracing; it describes a syndrome, not a specific child with specific problems. The definition assists in classifying children, not teaching them. Parents and teachers need to concentrate on the individual child. They need to observe both how and how well the child performs, to assess strengths and weaknesses, and develop ways to help each child learn. It is important to remember that there is a high degree of interrelationship and overlapping among the areas of learning. Therefore, children with learning disabilities may exhibit a combination of characteristics.

These problems may mildly, moderately, or severely impair the learning process.

Incidence

Many different estimates of the number of children with learning disabilities have appeared in the literature (ranging from 1% to 30% of the general population). In 1987, the Interagency Committee on Learning Disabilities concluded that 5% to 10% is a reasonable estimate of the percentage of persons affected by learning disabilities. The U.S. Department of Education (1993) reported that more than 4% of all school-aged children received special education services for learning disabilities and that in the 1991-92 school year over 2 million children with learning disabilities were served. Differences in estimates perhaps reflect variations in the definition.

Characteristics

Learning disabilities are characterized by a significant difference in the child's achievement in some areas, as compared to his or her overall intelligence.

Students who have learning disabilities may exhibit a wide range of traits, including problems with reading comprehension, spoken language, writing, or reasoning ability. Hyperactivity, inattention, and perceptual coordination problems may also be associated with learning disabilities. Other traits that may be present include a variety of symptoms, such as uneven and unpredictable test performance, perceptual impairments, motor disorders, and behaviors such as impulsiveness, low tolerance for fustruation, and problems in handling day-to-day social interactions and situations.

Learning disabilities may occur in the following academic areas:

1. Spoken language: Delays, disorders, or discrepancies in listening and speaking;
2. Written language: Difficulties with reading, writing, and spelling;
3. Arithmetic: Difficulty in performing arithmetic functions or in comprehending basic concepts;

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4. Reasoning: Difficulty in organizing and integrating thoughts; and
5. Organization skills: Difficulty in organizing all facets of learning.

Educational Implications

Because learning disabilities are manifested in a variety of behavior patterns, the Individual Education Program (IEP) must be designed carefully. A team approach is important for educating the child with a learning disability, beginning with the assessment process and continuing through the development of the IEP. Close collaboration among special class teachers, parents, resource room teachers, regular class teachers, and others will facilitate the overall development of a child with learning disabilities.

Some teachers report that the following strategies have been effective with some students who have learning disabilities:

- Capitalize on the student's strengths;
- Provide high structure and clear expectations;
- Use short sentences and a simple vocabulary;
- Provide opportunities for success in a supportive atmosphere to help build self-esteem;
- Allow flexibility in classroom procedures (e.g., allowing the use of tape recorders for note-taking and test-taking when students have trouble with written language);
- Make use of self-correcting materials, which provide immediate feedback without embarrassment;
- Use computers for drill and practice and teaching word processing;
- Provide positive reinforcement of appropriate social skills at school and home; and
- Recognize that students with learning disabilities can greatly benefit from the gift of time to grow and mature.

Resources

Journal of Learning Disabilities. Available from Pro-Ed, 8700 Shoal Creek Blvd., Austin TX 78758. Telephone: (512) 451-3246.)

Silver, L. (1991). *The misunderstood child: A guide for parents of children with learning disabilities* (2nd ed.). New York, NY: McGraw Hill Book Co. (Available from McGraw Hill Retail, 13311 Monterey Lane, Blue Ridge Summit, PA 17294. Telephone: (717) 794-5461.)

Smith, S. (1981). *No easy answers.* New York, NY: Bantam Books. (Available from Bantam, 2451 South Wolf Rd., Des Plains, IL 60018. Telephone: 1-800-223-6834.)

Organizations

Council for Learning Disabilities (CLD)
P.O. Box 40303
Overland Park, KS 66204
(913) 492-8755

Division of Learning Disabilities
Council for Exceptional Children
1920 Association Dr.
Reston, VA 22091-1589
(703) 620-3660

Learning Disabilities Assn. of America (LDA)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515
(412) 341-8077

National Center for Learning Disabilities
99 Park Avenue
New York, NY 10016
(212) 687-7211

National Network of Learning Disabled Adults (NNLDA)
P.O. Box 32611
Phoenix, AZ 85064
(602) 941-5112

Orton Dyslexia Society
Chester Building, Suite 382
8600 LaSalle Road
Baltimore, MD 21286-2044
(410) 296-0232
(800) 222-3123 (Toll Free)

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MISCONCEPTIONS ABOUT PERSONS WITH LEARNING DISABILTIES

MYTH > All students with learning disabilities are brain damaged.	**FACT** > Although more students with learning disabilities show evidence of damage to the central nervous system (CNS) than their nondisabled peers, many of them do not. Many authorities now refer to students with learning disabilities as having CNS dysfunction, which suggests a malfunctioning of the brain rather than actual tissue damage.
MYTH > IQ-achievement discrepancies are easily calculated.	**FACT** > A complicated formula determines a discrepancy between a student's IQ and his or her achievement.
MYTH > Standardized achievement tests are the most useful kind of assessment device for teachers of students with learning disabilities.	**FACT** > Standardized achievement tests do not provide much information about why a student has achievement difficulties. Informal reading inventories and formative evaluation measures give teachers a better idea of the particular problems a student is experiencing.
MYTH > We need not be concerned about the social-emotional well-being of students with learning disabilities because their problems are in academics.	**FACT** > Many students with learning disabilities do also develop problems in the social-emotional area.
MYTH > The most serious problem of children who are hyperactive is their excessive motor activity.	**FACT** > Although children who are hyperactive do exhibit excessive motor activity, most authorities now believe that their most fundamental problems lie in the area of inattention.
MYTH > Medication for children with attention-deficit disorder is over-prescribed and presents a danger for many children.	**FACT** > Some children receive medication who do not need it, but there is little evidence that vast numbers are inappropriately medicated. Medication can be an important part of a total treatment package for persons with attention-deficit disorder.
MYTH > Most children with learning disabilities outgrow their disabilities as adults.	**FACT** > Learning disabilities tend to endure into adulthood. Even most of those who are successful must learn to cope with their problems and show extraordinary perseverance.

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Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 161

Redbook Vol 167 (1) MAY, 1986

"I COULDN'T READ UNTIL I WAS 18"

Cher still can't spell or understand the words on a billboard. She has trouble dialing the phone and making change. At the age of 30 her problem was diagnosed as dyslexia. "Sometimes I feel so stupid. I don't know what I'd do if I had a regular job," she says. Here, for the first time, Cher talks about the disability that has caused her such pain.

BY LINDA KONNER

Cher, who has always exposed herself to merciless criticism for her hairdos, her clothes and her men, has recently opened herself up to further pain and humiliation by admitting publicly that she suffers from dyslexia. "I'm insecure about everything. It doesn't take much to shake my confidence to the bone," she says, and little wonder: The simplest tasks still baffle her. Her dyslexia made her school years a nightmare—she dropped out in 11th grade—and her acting career a struggle. Yet she has successfully managed to establish herself as an actress and is finally, at the age of 40, gaining the respect that has eluded her for so long.

Q. How did you feel when you first found out that you had dyslexia?
A. Suddenly things made a lot of sense. I never read in school. The first book I ever read was when I was 18 or 19 years old, and it was called *The Saracen Blade* by Frank Yerby. When I was in school, it was really difficult. Almost everything I learned, I had to learn by listening. I just couldn't keep up with everybody else. You can be really intelligent, but if you don't have a way of letting people know, you seem really stupid. My report cards always said that I was not living up to my potential. Teachers would see that I was a bright girl in class, and then I would hand in papers that you couldn't read. Also, I could never do the work quickly enough—most of the tests were timed.

Q. What were your grades like?
A. They were very sporadic. I got really bad grades—D's and F's and C's—in some classes, and A's and B's in other classes. My mother would get exasperated with me sometimes: She just could not understand why I could do so well in one class one semester and fail the next semester. And I never could understand it either. Some things were so difficult. But eventually I left school—in the second week of 11th grade. I just quit. I was sitting there one day and I just got up and said, "I'm not going back."

Q. It's understandable that you wouldn't like school if you were having such a hard time.
A. Well, I believe that, for the most part, school is a very boring place for very bright minds, you know? I think what school does half the time is cut out your creativity and just make you fit into society. I don't think school is the place to really learn very much. It's evident if you see what's happening in the country—you know, there are so many people who can't pass a civil service exam, or can't read. In Los Angeles, instead of using the word *Walk* [on street signs], they show a person walking, because some people can't read a sign.

Q. When was your dyslexia condition first diagnosed?
A. When I was 30.

Q. You found out about it when you took Chastity to be tested?
A. Yes. She's very intelligent, but she just did so badly in school, and she was having such a hard time. Then I sent her to a special school, which was really a drag, because a lot of the kids in the school had emotional problems and she doesn't. But she just felt that she was stupid because her oral scores were so much higher than her written scores.

Q. What did you do next?
A. One of the doctors who had tested her recommended that I take her to a dyslexia center in Santa Monica. When I went in there, I said to the lady, "I know Chastity is really smart—she's just like me." The woman said, "What do you mean?" and we started talking about it, and that's when we found out we both had it.

Q. Now that Chastity understands the problem, she must feel better.
A. Yes, she feels a lot better. She's now go-

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ing to the High School of Performing Arts and she's doing great, but she has to work really hard at it. She has to study longer than most kids with her amount of intelligence. That's the problem, you know.

Q. As for your dyslexia, how does it affect you now on a day-to-day basis?
A. There are still things that I do that make me feel really stupid. Like, the other day I couldn't figure out how much money to give the cab driver. In my mind what I did made sense, but he was just furious that I didn't give him a decent tip. Dialing long distance is difficult. If I really concentrate on it, I can do it. But if there's a number—for example, 472, I'll see 427. And the more numbers there are, the harder it is for me to retain them in sequence. And I see billboards that don't exist. Like, I'll see four words on a billboard, and I'll just put them together in my own way. It'll make sense to me, but it won't have anything to do with what the billboard actually says.

Q. Once you were diagnosed, did doctors do anything to help you?
A. No, but I've pretty much got my own way of handling it. Like the reading—I read very slowly. Now, if I read a script once, I know it; I almost never have to look back at it. I guess your brain compensates. If I had a regular job—one that uses skills that most people have to use, like eye-word, eye-number skills—I don't know what I'd do. But for what I do, the way I read is only an inconvenience.

Q. What about reading from cue cards while you're performing?
A. I don't do that.

Q. How did you handle that when you were doing your TV shows?
A. Sonny read the cards and I studied the script.

Q. Did you ever find yourself in an embarrassing situation involving your dyslexia?
A. (laughs) Yes. I once went on an audition for a movie. I was supposed to meet the director and talk to him about a part, and he was going to see if I was right for it. Because he thought I was perfect, he wanted me to read. And I said, "I don't do this well." But he gave me the script. Then Jack Nicholson [the star of the movie] walks in. We were sitting there, and I started to read, and I am trying to explain to them that I don't do this well at all. But they didn't want to know about it. So we start to read, and when I was done, the director said, "It's a good thing I saw you in *Silkwood* yesterday, because that is definitely the worst cold reading I have ever heard." And I said, "Well, you know, I told you that's not what I do well."

(continued on page 174)

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"I COULDN'T READ UNTIL I WAS 18"

continued from page 125

Q. Did you explain why?
A. Not really, because it was a tense moment. It was terrible. I didn't get the part!

Q. How do you feel about doing cold readings for directors now?
A. I wouldn't do them now. I would never cold read for anybody. Look, in *Mask* I tested, and I k... what I was doing. It's like, I saw a show once where they were looking for tap dancers. There was this little boy from Spain, and he needed a job, and he was a flamenco dancer. He tried to tap dance, but he couldn't do it. But then, when he did what he *could* do, he did it better than all the people that were trying out for the tap dancing job. So it just wouldn't make sense for me to try to cold read if what they wanted to do was see what I did well.

Q. Now that there's no pressure on you to read, do you ever read for pleasure? Or is it still a struggle?
A. I read for pleasure constantly. I'm reading four books right now. I'm reading *The Mammoth Hunters*; I read the first two [Jean Auel books]. I'm reading *The Vampire Lestat*. I'm reading *Goddess* and *Drama of the Gifted Child*, a psychology book my boyfriend Josh [Donen] gave me.

Q. How do you feel now that the public knows about your dyslexia?
A. I could care less.

Q. What about your feelings about your image in general?
A. The way I dress and the way I look are my sense of expression and creativity; I don't feel like stifling that for anybody. I mean, I was going to get a Mohawk haircut one time, and Chastity threw herself against the door. She said, "You know, *you* should be doing this to *me*. I should be the one that wants a Mohawk, and you should be saying no." It's like, if Chas wants to dye her hair green and purple, it shouldn't make any difference; it's an expression of who she is. It's like that for me too. So I have a major reputation. It's amazing what a hairdo can give you! People think I'm really crazy because of the way I look. I think that's ... crazy.

Q. How do you think your image affects your children?
A. I think they're much cooler than most people. I think they're both very proud of me. They think I'm outrageous, and they laugh at the way I am sometimes; they get a kick out of me.

Q. Perhaps they can understand the way you dress because you're their mother and they love you. But what about the comments they may hear about you from their friends, or from strangers?
A. Chas goes to a school where the students are actors and actresses, and they're all pretty much into the work I do. Chas is really well-liked in school for herself, but I also remember that when *Mask* came out, her friends said, "Oh, Chas, I loved your mom in the movie." You know, lots of her friends have Mohawks. Kids are not as judgmental as adults. So most of Chas' friends think I'm really cool because I'm an adult, but I don't exactly look like an adult ... whatever that's supposed to mean.

As for Elijah ... One day he came home and he was really upset. He said, "So-and-so's grandmother said you're a whore." And I said, "Well, that's interesting. What did she base that on?" And he said, "I don't know, but I'm not going to talk to him anymore." We talked about it for a long time; I could tell he was pretty upset. But later, he came to the conclusion that he lives with me and he knows what kind of person I am. He realized that this woman was having a rough time in her life, and that it didn't have much to do with him or me.

Q. Does Chastity generally accept you better than Elijah does?
A. Yes. I think boys are just so much more vulnerable than girls. Chastity's always had the most amazing inner strength. She's never really liked [other] kids that much; she's always been around adults and had an adult kind of philosophy about things. The only thing I can ever remember her being really upset about lately was when she got into the High School of Performing Arts. Right afterward the school got all this video equipment, and some kids started a rumor that Chastity got in because I bought all the equipment. She was really angry about that. But I don't think the way I've led my life has interfered with her that much. It might have when we were back in California, when I was leaving her father. I know that was a real difficult time for her.

Q. How did you explain your breakup with Sonny to Chastity?
A. Well, until recently—maybe a couple of years ago—I never said very much to her about Sonny. I try to be really positive, because she felt bad that he hadn't done as well [as I had] after the breakup. One day she was giving me some flak because I didn't invite her father to something—and I said, "You know, I've never said anything bad about your father and I've never gone into any of the reasons. But you're old enough for me to tell you that it's impossible for me to be friends with your father, because I just don't like him."

Q. How old was she when you said that?
A. About 15½.

Q. How did she take it?
A. She wasn't crazy about it at all.

Q. It must be hard for a child to hear that her parents don't like each other.
A. Oh, I'm sure of it. But, the truth is, you can only be hurt in your life by someone so much, and then you have to protect yourself or it doesn't make any sense. For me to be around Sonny is like walking into a fire.

Q. How would you describe the relationship you had with Sonny?
A. It was like I was a black person working on a plantation for a benevolent boss. Without your freedom, it doesn't make any difference who your master is. For a long time, I acted toward him in a way that was very different from the way I felt. And I'm sorry I feel this way—I would prefer to be absolutely friendly and enjoy being around him. It would make my life a lot easier. But I don't think I ever knew Sonny at all. First of all, what can you know at 16? Not very much. But also, he didn't want to share himself. He thought that if I knew about him, I would have some kind of power that he just wasn't ready to give up. That's something we all do, but [to be doing that for] 11 years is a long time. I mean, if you can't trust someone ... He was 28 when I met him, and he'd been trying for 10 years to be a singer. Then, all of a sudden, in a matter of a year, we became famous. He said that he knew from the time he saw me that it was going to happen. But he was always afraid that if I knew I was talented or pretty or any of the other things he thought I was, that I would leave him. I've been working on a song for a new album; it's really autobiographical. I've got one verse in there about Sonny he's not going to like at all. It goes:

He stole life and heart and beauty,
Said he did it for my good,
Said he always knew I'd leave him,
So he crushed me while he could.
There's no answers, there's no justice,
There's just eyes too blind to cry.
It's no wonder I'm the phoenix,
My salvation that I've died.

Q. You feel then that he withheld from you the encouragement you really needed?
A. You know, it was strange—he gave it on certain levels, like on a work level. He was always saying, "You can do it" [about my work]. That's why we made better [business] partners than husband and wife. If we had only stuck to working together, it would have been great.

Q. What do you think about the whole idea of marriage now?
A. Marriage doesn't interest me. It would if it was important to someone that I cared about. As something that *I'm* seeking? I don't know if it works for me. I don't know if I'm ready to be married.

(continued on page 177)

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"I COULDN'T READ UNTIL I WAS 18"

continued from page 174

Q. Even as you turn 40, even after two marriages?
A. As I was turning 30 I was a lot more ready to be married; I *was* married [to rock singer Gregg Allman]. Marriage sounds fabulous in theory. But the kind of work I'm in is not exactly noted for long-lasting relationships of any kind.

Q. Would you say your work makes you self-centered?
A. I'm certainly self-centered, but I'm really giving in a relationship; while I'm in it, it's very important. I mean, I'm not perfect, but as a partner I think I'm really loving and giving. It's just that it only lasts so long.

Q. Does that mean you don't think anybody can sustain a good relationship over a long period of time?
A. Look, I sustained a *bad* relationship over a long period of time. The older I get, the less patience I've got for sustaining anything that doesn't work over a long period of time. If it worked—and I'm willing to work on things—I would be in it for a long time. But I also want to be creative, and I don't know that creativity necessarily has too much to do with marriage. I also like to spend a lot of time alone.

Q. How do you spend your time alone?
A. I like to read. I like to exercise. I like to write. I like the freedom of not having to answer to anybody. You know, I think that being with Sonny did a lot of things that were not so healthy for me—I mean, I had to have a reasonable place to go to before I could [get permission from Sonny to] go out of the house. And because of that, I've had a big backlash. I don't want anybody to ask me where I'm going—if I want to go someplace, I really want to do it. Thank God, I have my kids; kids are usually so much more understanding than husbands. For example, when I was doing *Mask*, I would get up at 5:30 in the morning, and I would work out for an hour until I was picked up to go to the studio. I would come home at 7:30 at night, and I would fall into bed. I couldn't give anything to anyone. The kids would come and sit on the bed, and we'd talk—sometimes I'd fall asleep talking. I didn't even have that much energy to give them on weekends. It's hard to explain that to a man, because he'd take it personally.

Q. Does your wanting to stay single have anything to do with sex—a desire to avoid sexual fidelity?
A. No. I'm so monogamous it's disgusting. I'm not very liberated or New Age; if I find somebody that I really like, I just don't want to be with anybody else. I'm not a dater at all. I have such a reputation; it's just that my relationships are publicized.

Q. What's your ideal man like?
A. I've just been with the ideal man. His name is Josh Donen, and he's the most fabulous man I've ever known. He's bright, we're in the same business [he's a movie producer], we've got everything to talk about, he's handsome, he cracks me up constantly, he's a fabulous father to my kids. There's nothing wrong with him. Even my mother is crazy about him. She says, "Cher, come home to California. Don't stay in New York; are you crazy? What's the matter with you?" I've never met anybody like him. He's like a dream man. He's a prince.

Q. So what's the problem?
A. His work keeps him stuck in L.A.; he has an extremely demanding job. And whenever I come to New York, I really want to be here. It's so hard for me to live in Los Angeles; I really don't like it there. Also he wants to get married—and that just really scares me to death.

Q. If there were one thing about yourself that you could change, what would it be?
A. I would not want to be so insecure. That insecurity stifles everything. As I go on in life, I become more secure in some areas and less secure in others that I used to be more secure in. I guess it's a trade-off.

Q. What are you most insecure about?
A. Everything from my ability as an actress to my ability as a mother to how I look. It doesn't take much to shake my confidence to the bone. But then I keep coming back. So, if I'm going to keep coming back, I would just like to tell myself once and for all that I'll be okay, so I don't have to keep going through the drama.

Q. Do you think your ability to bounce back makes people like you?
A. Yes. I'm a survivor, and people respect that. You know, I was about as down and out as anyone can be in my profession [after the TV shows went off the air], and all of a sudden, I just came back to life. I've done that a whole bunch of times. Also, people kind of like me in spite of myself.

Q. What do you mean?
A. I'm one of those people that's kind of likable; you just kind of like them. For instance, when I go on the *Donahue* show, I always think, "Oh, these women are going to kill me." And yet, they don't. Part of it is because I'm not totally full of sh—. I don't really hide my mistakes—I mean, it would be impossible to try to hide them. But I feel like I have some kind of special dispensation. People like me in spite of the fact that if they saw me walking down the street and I wasn't Cher, they wouldn't like me at all. ●

PERK UP A POTATO
One potato. Two potato. Three potato. Four. When you add Campbell's® Cheddar Cheese Soup, four potatoes become more than potatoes. Here's a Campbell's recipe that will perk up your potatoes:
1 can (11 oz.) Campbell's Condensed Cheddar Cheese Soup
1 cup cooked broccoli flowerets
2 tbsp. sour cream
½ tsp. Dijon mustard
4 large baked potatoes
Chopped pimiento
In 1½ qt. saucepan over medium heat, stir soup. Stir in broccoli, sour cream and mustard. Heat thoroughly; stir occasionally. Split potatoes; fluff with fork. Serve sauce over potatoes. Garnish with chopped pimiento. 4 servings.
Campbell's
Cheddar Cheese SOUP
CAMPBELL'S SOUP MAKES GOOD FOOD

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XI. Visual Impairments

- General Information about Visual Impairments (NICHCY Fact Sheet)
- Misconceptions about Persons with Visual Impairments
- How Not to Help A Person Who is Blind and Lost
- Mainstreaming Case History: Troy was Blind
- America's Boswell Drives Into the Dark

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free) (202) 416-0300 (Local, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

General Information About

VISUAL IMPAIRMENTS

Definition

The terms partially sighted, low vision, legally blind, and totally blind are used in the educational context to describe students with visual impairments. These terms are defined as follows:

- "Partially sighted" indicates some type of visual problem has resulted in a need for special education;
- "Low vision" generally refers to a severe visual impairment, not necessarily limited to distance vision. Low vision applies to all individuals with sight who are unable to read the newspaper at a normal viewing distance, even with the aid of eyeglasses or contact lenses. They use a combination of vision and other senses to learn, although they may require adaptations in lighting, the size of print, and, sometimes, braille;
- "Legally blind" indicates that a person has less than 20/200 vision in the better eye or a very limited field of vision (20 degrees at its widest point); and
- Totally blind students, who learn via braille or other non-visual media.

Visual impairment is the consequence of a functional loss of vision, rather than the eye disorder itself. Eye disorders which can lead to visual impairments can include retinal degeneration, albinism, cataracts, glaucoma, muscular problems that result in visual disturbances, corneal disorders, diabetic retinopathy, congenital disorders, and infection.

Incidence

The rate at which visual impairments occur in individuals under the age of 18 is 12.2 per 1,000. Severe visual impairments (legally or totally blind) occur at a rate of .06 per 1,000.

Characteristics

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appears, and overall functioning level of the child. Many children who have multiple disabilities may also have visual impairments resulting in motor, cognitive, and/or social developmental delays.

A young child with visual impairments has little reason to explore interesting objects in the environment and, thus, may miss opportunities to have experiences and to learn. This lack of exploration may continue until learning becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or understand nonverbal cues. Visual disabilities can create obstacles to a growing child's independence.

Educational Implications

Children with visual impairments should be assessed early to benefit from early intervention programs, when applicable. Technology in the form of computers and low-vision optical and video aids enable many partially sighted, low vision, and blind children to participate in regular class activities. Large print materials, books on tape, and braille books are available.

Students with visual impairments may need additional help with special equipment and modifications in the regular curriculum to emphasize listening skills, communication, orientation and mobility, vocation/career options, and daily living skills. Students with low vision or those who are legally blind may need help in using their residual vision more efficiently and in working with special aids and materials. Students who have visual impairments combined with other types of disabilities have a greater need for an interdisciplinary approach and may require greater emphasis on self care and daily living skills.

Resources

American Foundation for the Blind. (1993). *AFB directory of services for blind and visually impaired persons in the United States and Canada* (24th ed.). New York, NY: Author.

Curran, E.P. (1988). *Just enough to know better (A braille primer).* Boston, MA: National Braille Press.

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Dodson-Burk, B., & Hill, E.W. (1989). *An orientation and mobility primer for families and young children* (Item 1576). New York, NY: American Foundation for the Blind.

Farrell, K.A. (1985). *Reach out and teach: Materials for parents of visually handicapped and multi-handicapped young children* (Item 2084). New York: American Foundation for the Blind.

Hazekamp, J., & Huebner, K.M. (1989). *Program planning and evaluation for blind and visually impaired students: National guidelines for educational excellence* (Item 155x). New York, NY: American Foundation for the Blind.

Holbrook, M.C. (Ed.). (in press). *Children with visual impairments: A parents' guide.* Rockville, MD: Woodbine. [Telephone: 1-800-843-7323 (outside DC area); (301) 468-8800 (in DC area).]

Huebner, K.M.,& Swallow, R.M. (1987). *How to thrive, not just survive: A guide to developing independent life skills for blind and visually impaired children and youth* (Item 1487). New York, NY: American Foundation for the Blind.

Scott, E., Jan, J., & Freeman, R. (1985). *Can't your child see?* (2nd ed.). Austin, TX: Pro-Ed. [Available from Pro-Ed, at (512) 451-3246.]

Organizations

American Council of the Blind Parents
c/o American Council of the Blind
1515 15th St. N.W., Suite 720
Washington, D.C. 20005
(202) 467-5081; (1-800) 424-8666

American Foundation for the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000; (1-800) AFBLIND (Toll Free Hotline)
For publications, call: (718) 852-9873

Blind Children's Center
4120 Marathon Street
Los Angeles, CA 90029-0159
(213) 664-2153; (1-800) 222-3566

Division for the Visually Handicapped
c/o Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660

National Association for Parents of the Visually Impaired, Inc.
P.O. Box 317
Watertown, MA 02272
(817) 972-7441

National Association for Visually Handicapped
22 West 21st Street, 6th Floor
New York, NY 10010
(212) 889-3141

National Braille Association, Inc. (NBA)
1290 University Avenue
Rochester, NY 14607
(716) 473-0900

National Braille Press
88 St. Stephen Street
Boston, MA 02115
(617) 266-6160; (1-800) 548-7323

National Eye Institute
National Institutes of Health
U.S. Department of Health & Human Services
Building 31, Room 6A32
Bethesda, MD 20892
(301) 496-5248

National Federation of the Blind, Parents Division
c/o National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314

National Library Services for the Blind and Physically Handicapped
Library of Congress
1291 Taylor Street, N.W.
Washington, D.C. 20542
(202) 707-5100; (1-800) 424-8567

National Retinitis Pigmentosa Foundation
1401 Mt. Royal Avenue, Fourth Floor
Baltimore, MD 21217
(410) 225-9400; (410) 225-9409 (TT)
(1-800) 683-5555 (Toll Free)

National Society to Prevent Blindness
500 E. Remington Road
Schaumburg, IL 60173
(708) 843-2020; (1-800) 221-3004 (Toll Free)

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VISUAL DISABILITIES

THINGS TO KNOW:

- The definition of legally blind is 20/200 vision with best correction. Many people, however, who are considered blind do have *some* sight.
- Many people who are blind view their blindness more as an inconvenience than as a disability.

THINGS TO DO: INTRODUCTIONS

- Introduce yourself. Identify who you are and what your job or role is. Be patient – it may take several introductions for the person who is blind to recognize you.
- Introduce anyone who is with you and give any pertinent information about them. For example, "On my right is Lucy Smith. She is vice-president."
- When conversing in a group, say the name of the person to whom you are speaking. This gives the person who is blind a vocal clue.
- Speak to a person who is blind the same way you would to anyone else. People who are blind can hear – they just can't see. So speak in a normal tone of voice, don't shout.
- When you move, let the person who's blind know where you are – so you won't leave him/her talking to "empty air."

Continued ...

THINGS TO DO: ASSISTING

- If you encounter a person who is blind and seems to need help, offer your services by saying, "May I help you?" This lets the person know you are willing to assist when necessary, but it also indicates your confidence in his or her ability to function independently.

- Allow the person with the visual disability to take your arm, don't grab theirs. It is important that you let them control their own movements.

THINGS TO DO: GIVING DIRECTIONS

- When giving directions, be specific. Saying, "Over there" doesn't provide much assistance to someone who can't see where you're pointing. Instead, "Walk straight ahead twenty feet, then go up two steps" or "Turn right at the second door on your left" is more helpful.

- When directing a blind person to a seat, place the person's hand on the back or arm of the chair and say, "Your hand is on the left arm of the chair."

- In a restaurant, you can be of assistance by helping the person locate food on the plate. Using a clock system is useful here: "potatoes are at two o'clock and meat is at 10 o'clock."

GUIDE DOGS

- Obtain permission before interacting with someone's guide dog. Commands given to the guide dog by a person other than the master can be confusing to the animal. For safety, it is important that the guide dog remain alert and focused while on duty (in harness).

ARE YOU NERVOUS BECAUSE I AM BLIND?

Close your eyes a moment. Are you a different person than you were with your eyes open? Of course not, and neither am I.

When we walk together, let me take your arm. I'll keep a half-step behind, so I can anticipate steps and curbs.

Speak to me when you enter the room. Introduce me to everyone else in the room, otherwise I may not know they are there. Tell me if there is a dog or cat in the room. Then guide my hand to a chair.

Describe the furniture placement to me, and anything I might be apt to bump into, such as a door left ajar, or a child's toys on the floor.

If we go to a restaurant, please read the menu to me, including the prices. I may ask for help cutting my meat. Describe the food placement to me, as on a clock face (potatoes at 12, carrots at 3, steak at 6, a tomato slice and parsley at 9,) Then I'll do just fine.

Do you wonder why I am blind? Don't be shy. I may be just as anxious to tell you as you are to ask.

Don't avoid words like "see." I use them, too. Don't stumble over "visually handicapped" or "partially sighted." I am blind. I know it. You know it. Be comfortable with it.

You need not raise your voice to me. I probably hear just as well as you do.

If I am your house guest, show me the bathroom, closet, dresser, bed, windows, lights and electric outlets for my razor. I like to know if the lights are on. Also, take me on a brief tour of your kitchen, so I need not bother you every time I want a glass of water.

I am not a blind person. I am just a person who happens to be blind. Please walk beside me, and be my friend.

MISCONCEPTIONS ABOUT PERSONS WITH VISUAL IMPAIRMENTS

MYTH > People who are legally blind have no sight at all.	**FACT** > Only a small percentage of those who are legally blind have absolutely no vision. Many have a useful amount of functional vision.
MYTH > People who are blind have an extra sense that enables them to detect obstacles.	**FACT** > People who are blind do not have an extra sense. Some can develop an "obstacle sense" by noting the change in pitch of echoes as they move toward objects.
MYTH > People who are blind automatically develop better acuity in their other senses.	**FACT** > Through concentration and attention, individuals who are blind can learn to make very fine discriminations in the sensations they obtain. This is not automatic but rather represents a better use of received sensations.
MYTH > People who are blind have superior musical ability.	**FACT** > The musical ability of people who are blind is not necessarily better than that of sighted people but many people who are blind pursue musical careers as one way in which they can achieve success.
MYTH > Braille is not very useful for the vast majority of people who are blind; it should only be tried as a last resort.	**FACT** > Very few people who are blind have learned Braille, primarily due to fear that using Braille is a sign of failure and to an historical professional bias against Braille. Authorities acknowledge the utility of Braille for people who are blind.
MYTH > Braille is of no value for those who have low vision.	**FACT** > Some individuals with low vision have conditions that will eventually result in blindness. More and more, authorities think that these individuals should learn Braille to be prepared for when they cannot read print effectively.
MYTH > If people with low vision use their eyes too much, their sight will deteriorate.	**FACT** > Only rarely is this true. Visual efficiency can actually be improved through training and use. Wearing strong lenses, holding books close to the eyes, and using the eyes often cannot harm vision.
MYTH > Mobility instruction should be delayed until elementary or secondary school.	**FACT** > Many authorities now recognize that even preschoolers can take advantage of mobility instruction, including the use of a cane.
MYTH > The long cane is a simply constructed, easy to use device.	**FACT** > The National Academy of Sciences has drawn up specifications for the manufacture of the long cane and using it properly.
MYTH > Guide dogs take people where they want to go.	**FACT** > The guide dog does not "take" the person anywhere; the person must first know where he or she is going. The dog is primarily a protection against unsafe areas or obstacles.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 343.

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How Not to Help a Person Who Is Blind and Lost

When the sighted encounter someone who is lost, their natural inclination is to ask the person where he or she is headed. As the following entry in the diary of John M. Hull (1990) indicates, this question can lead to confusion when the person lost happens to be blind.

GETTING LOST — 8 November

I think it is David Scott Blackhall, in his autobiography *The Way I See Things* (London, Baker, 1971), who remarks how annoying he found it when people refused to answer his question about where he was and insisted on asking him where he was trying to get to. I share this experience.

Going home the other night I was turned out of my way by some construction work on one of the footpaths. By mistake I turned along a side street, and after a block or so, when I realized I had made a mistake somewhere, I was not sure exactly where I was. There were some chaps working on a car parked on the roadside. 'Excuse me', I said. 'Could you tell me please where I am? What is the name of this street?'

The chap replied, 'Where are you trying to get to?'

With what I hoped was a good-humored laugh, I said, 'Never mind about that, just tell me, please, what street this is?'

'This is Alton Road, You usually go up Bournbrook Road, don't you? It's just a block further along.'

I thanked him, and explained that I needed now to know exactly whereabouts on Alton Road I was so that I could get to Bournbrook Road. 'Which side of Alton Road am I on? If I face that way, am I looking towards Bristol Road or is it the other way?'

'You live high up Bournbrook Road, don't you? Well, if you take the next road to the left you'll be OK.'

But which way is 'left'? Does he mean me to cross the road or to stay on this side? At this point, the blind and sighted enter into mutual bafflement.

When a sighted person is lost, what matters to him or her is not where he is, but where he is going. When he is told that the building he is looking for lies in a certain direction, he is no longer lost. A sighted person is lost in the sense that he does not know where the building he is looking for is. He is never lost with respect to what street he is actually on; he just looks at the street sign on the corner of the block. It is his direction he has lost, rather than his position. The blind person lost has neither direction nor position. He needs position in order to discover direction. This is such a profound lostness that most sighted people find it difficult to imagine.

SOURCE: From *Touching the rock* by John M. Hull. Copyright © 1990 by John M. Hull. Reprinted by permission of Pantheon Books, a division of Random House, Inc., pp. 144–145.

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Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 351.

MAINSTREAMING

CASE HISTORY

TROY

TROY WAS BLIND

ALTHOUGH I'D BEEN TEACHING for more than 10 years, I was apprehensive about having a blind student in my class. How would I adapt my lessons to meet Troy's needs *and* my other students' needs? How could Troy participate in all our activities?

My state's school for the blind would provide braille textbooks for Troy. But the school didn't provide braille work sheets or supplementary materials, so I had to either send these to the school to be converted to braille or figure out a way to adapt them. And I always needed a backup plan in case the materials didn't arrive in time.

When I met Troy, I found him to be friendly, outgoing, and eager to learn. He quickly found his way around, and I could tell by his facial expressions that he was excited to be in school.

I soon realized that Troy was an extremely skillful listener. I planned more oral lessons and tests so Troy could work with the rest of the class. His listening skills saved the day once when we completed our assignments early and the other students asked to read a play. We didn't have a braille copy, but I asked another student to prompt him, and Troy was able to play a part. His face glowed.

Our unit on graphs and diagrams brought new challenges. But I was able to make this unit tactile so Troy could read the information. I made circle graphs using heavy-duty aluminum foil and a dressmaker's wheel and bar graphs using tiny pinpricks on heavy braille paper. The school for the blind added the statistics in braille.

I used textured materials to make diagrams for Troy. For one unit, I made a diagram of rock layers using a smooth section, one with dots of glue, and one with tiny pinpricks.

Because Troy couldn't see the pictures in our books, I had his classmates describe them to him in detail. Not only did Troy understand the information better, but so did the rest of the class.

Art is an area that's traditionally closed to blind students. My students loved illustrating stories we read, and I could see that Troy wanted to try drawing too. When we read *The Lion, the Witch, and the Wardrobe*, I found I had a tape of songs to go with the book. I gave my students paper and asked them to close their eyes, listen, and draw to the flow of the music—all without peeking. Troy was excited when the other students found pictures in his drawing.

Throughout that school year, my class and I learned to look at our world in a new way. Troy taught us that, with some extra effort, a positive attitude, and a little help from friends, a blind student could do anything we could do—and more. ❍

Troy may have been born blind, but when he entered Eileen Walcik's 7th-grade reading class at Smith Middle School, he could see his goal clearly—to be the same as the other students. All his life, Troy had worked extra hard to keep up with kids his age. He'd taught himself to skateboard, mastered the drums, and learned music by ear. Now, at the age of 13, fitting in had become even more important. Walcik quickly found that the challenge of helping Troy required *her* to see new ways of doing things.

Eileen Walcik teaches 6th- and 7th-grade English and reading (talented and gifted) at Smith Middle School in Fort Hood, Tex.

DUDLEY DOUST ON A REMARKABLE PLAYER

After he had stooped to feel the texture of the grass, and finger the edge of the cup, Charley Boswell paced with his caddie across the green to his ball. He counted as he went . . . 48, 49, 50 feet. "It's mostly downhill," said his caddie, crouching to line up the face of Boswell's putter. "Take off about 10 feet, and putt it like a 40-footer."

Boswell stroked the ball. It sped across the green, climbed and fell, curved, slowed down and dropped with a rattle into the hole. Boswell grinned: "Did you see that one?" Yes, I had seen it. But he hadn't. Charley Boswell is blind. In fact, he is one of the most remarkable blind sportsmen in the world and playing off a handicap as low as 12, he has won the United States Blind Golfers' Association Championship 17 times.

Putting, oddly enough, is one of Boswell's strong departments. Given, of course, the fact that his caddie reads the putt, his execution is immaculate. "A tip that we blind golfers can pass on to the sighted player," he said, "I don't worry about the breaks on a green. Don't try to curb your putt because, as Bobby Jones always said, every putt is a straight putt and let the slopes do the work."

A few weeks ago I met Boswell in California, where he was playing a benefit match for the Braille Institute of America. He had come up from Alabama, where he is the State Commissioner in the Department of Revenue, a remarkable enough job, and now he was walking to the second tee on a course in the lush Coachelle Valley. A wind blew down from the mountains. "Funny thing," he said, "wind is really the only thing that bothers me. It affects my hearing, and that ruins my sense of direction."

On the second tee his caddie, who is his home professional back in Alabama, lined up the face of Boswell's driver and stepped away. Boswell, careful not to lose this alignment, did not waggle his clubhead. He paused, setting up some inner rhythm, and swung with the certainty of a sighted player. He groaned as the ball tailed off into a slice.

"There are two ways I can tell if I hit a good shot," he said, frowning. "I can feel it through the clubhead and, more important, I finish up high on my follow-through. Come on, let's walk. I can't stand golf carts—they bother my judgment of distance."

Boswell has been walking down darkened fairways since shortly after the Second World War. Blinded when a German antitank gun scored a direct hit on his vehicle in the Ruhr, he was sent back to an American hospital for rehabilitation. A former gridiron footballer and baseball player, Boswell did not take easily to pampered, supervised sport.

"I tried swimming, and it bored me. I tried horseback riding until I rode under a tree and got knocked off. I tried ten-pin bowling, and that wasn't any good either—I fell over the ball-track." He laughed, idly swinging his club as he walked. "Then one day this corporal came in and suggested we play golf. I told him to get the hell out of my room."

Boswell had never swung a golf club in his life but, a few days later, aged 28, he gave it a try: "He handed me a brassie. I took six practice swings, and then he teed one up and I hit it dead centre, right out of the sweet spot. I tell you, I was lucky. If I'd missed the ball that first time I would have quit golf." There are no false heroics about Boswell.

Some holes later he, or rather we, found his ball in a bunker. The bunker shot was clearly the most difficult shot in Boswell's bag. Playing it required him to break two Rules of Golf: he not only needed his usual help from someone to line up his club but, to avoid topping the ball, or missing it altogether, he had to ground his club in the sand. "Also, I can't get fancy and cut across the ball," he said. "I have to swing square to the line of flight. I have to play it like an ordinary pitch."

These handicaps, he later pointed out, were in part counterbalanced by the actual advantages of being blind on a golf course. Boswell, for instance, is never tempted to play a nine-iron when a seven-iron will do the job. "In a match blind players play the course, not their opponents, because we can't see what they're doing anyway," he said, on the way to a score of 91 which, for him, was neat but not gaudy. "You know, I was once playing with Bob Hope, and he said: 'Charley, if you could see all the trouble on this golf course, you wouldn't be playing it.' And I suppose he was right."

SOURCE: Dudley Doust, *Sunday Times*, London, February 6, 1977. Reprinted by permission.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 352.

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XII. Hearing Impairments

- Deafness: A Fact Sheet (NICD Sheet)
- Misconceptions about Persons with Hearing Impairments
- Up To The Challenge

National Information Center on Deafness

NEW PHONE NUMBER.
(202) 416-0300 (VOICE/TT)

DEAFNESS: A FACT SHEET

This fact sheet was written cooperatively by the National Information Center on Deafness and the National Association of the Deaf.

Introduction

An estimated 21 million Americans have some degree of hearing impairment. Hearing impairments affect individuals of all ages, and may occur at any time from infancy through old age. The degree of loss may range from mild to severe. This variability in age at onset and degree of loss plus the fact that each individual adjusts differently to a loss of hearing makes it impossible to define uniformly the consequences of a loss.

Although the National Center for Health Statistics through its Health Interview Survey has been able to estimate the number of people with hearing impairments, there have been no recent national surveys which can be used to estimate the number of people who are deaf. As a result, estimates for the number of deaf people range anywhere from 350,000 to two million.

Audiological/Medical Information

There are four types of hearing loss, each of which can result in different problems and different possibilities for medical and nonmedical remediation.

Conductive hearing losses are caused by diseases or obstructions in the outer or middle ear (the conduction pathways for sound to reach the inner ear). Conductive hearing losses usually affect evenly all frequencies of hearing and do not result in severe losses. A person with a conductive hearing loss usually is able to use a hearing aid well, or can be helped medically or surgically.

Sensorineural hearing losses result from damage to the delicate sensory hair cells of the inner ear or the nerves which supply it. These hearing losses can range from mild to profound. They often affect certain frequencies more than others. Thus, even with amplification to increase the sound level, the hearing impaired person perceives distorted sounds. This distortion accompanying some forms of sensorineural hearing loss is so severe that successful use of a hearing aid is impossible.

Mixed hearing losses are those in which the problem occurs both in the outer or middle and the inner ear.

A **central** hearing loss results from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself.

Among the causes of deafness are heredity, accident, and illness. An unborn child can inherit hearing loss from its parents. In about 50 percent of all cases of deafness, genetic factors are a probable cause of deafness. Environmental factors (accident, illness, ototoxic drugs, etc.) are responsible for deafness in the remaining cases. Rubella or other viral infections contracted by the pregnant mother may deafen an unborn child. Hazards associated with the birth process (for example, a cut-off in the oxygen supply), may affect hearing. Illness or infection may cause deafness in young children. Constant high noise levels can cause progressive and eventually severe sensorineural hearing loss, as can tumors, exposure to explosive sounds, heavy medication, injury to the skull or ear, or a combination of these factors.

Central hearing loss may result from congenital brain abnormalities, tumors or lesions of the central nervous system, strokes, or some medications that specifically harm the ear.

The detection and diagnosis of hearing impairment have come a long way in the last few years. It is now possible to detect the presence of hearing loss and evaluate its severity in a newborn child. While medical and surgical techniques of correcting conductive hearing losses have also improved, medical correction for sensorineural hearing loss has been more elusive. Current research on a cochlear implant which provides electrical stimulation to the inner ear may lead to important improvements in the ability to medically correct profound sensorineural hearing loss.

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Educational Implications

Deafness itself does not affect a person's intellectual capacity or ability to learn. Yet, deaf children generally require some form of special schooling in order to gain an adequate education.

Deaf children have unique communication needs. Unable to hear the continuous, repeated flow of language interchange around them, deaf children are not automatically exposed to the enormous amounts of language stimulation experienced by hearing children during their early years. For deaf children, early, consistent, and conscious use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay. Without such assistance from infancy, problems in the use of English typically persist throughout the deaf child's school years. With such assistance, the language learning task is easier but by no means easy.

This problem of English language acquisition affects content areas as well. While the academic lag may be small during the primary grades, it tends to be cumulative. A deaf adolescent may be a number of grade levels behind hearing peers. However, the extent to which hearing impairment affects school achievement depends on many factors—the degree and type of hearing loss, the age at which it occurred, the presence of additional handicaps, the quality of the child's schooling, and the support available both at home and at school.

Many deaf children now begin their education between ages one to three years in a clinical program with heavy parental involvement. Since the great majority of deaf children—over 90 percent—are born to hearing parents, these programs provide instruction for parents on implications of deafness within the family. By age four or five, most deaf children are enrolled in school on a full-day basis. Approximately one-third of school-age deaf children attend private or public residential schools. Some attend as day students and the rest usually travel home on weekends. Two-thirds attend day programs in schools for the deaf or special day classes located in regular schools, or are mainstreamed into regular school programs. Some mainstreamed deaf children do most or all of their schoolwork in regular classes, occasionally with the help of an interpreter, while others are mainstreamed only for special activities or for one or two classes.

In addition to regular school subjects, most programs do special work on communication and language development. Class size is often limited to approximately eight children to give more attention to the children's language and communication needs.

At the secondary school level, students may work toward a vocational objective or follow a more academic course of study aimed at postsecondary education at a regular college, a special college program for deaf students (such as Gallaudet University or the National Technical Institute for the Deaf) or one of the 100 or more community colleges and technical schools that have special provisions for deaf students.

Communication: Some Choices

Communication is an important component of everyone's life. The possible choices for communication involve a variety of symbol systems. For example, you may communicate in English through speaking and writing. Despite your skills, you probably cannot communicate with someone whose only language is Chinese, even though that person also speaks, reads, and writes quite fluently.

In the United States, deaf people also use a variety of communication systems. They may choose among speaking, speechreading, writing, and manual communication. Manual communication is a generic term referring to the use of manual signs and fingerspelling.

American Sign Language

American Sign Language (ASL) is a language whose medium is visible rather than aural. Like any other language, ASL has its own vocabulary, idioms, grammar, and syntax—*different from English*. The elements of this language (the individual signs) consist of the handshape, position, movement, and orientation of the hands to the body and each other. ASL also uses space, direction and speed of movements, and facial expression to help convey meaning.

Fingerspelling

When you spell with your fingers, you are in effect "writing in the air." Instead of using an alphabet written on paper, you are using a manual alphabet, that is, one with handshapes and positions corresponding to each of the letters of the written alphabet.

Conversations can be entirely fingerspelled. Among deaf people, however, fingerspelling is more typically used to augment American Sign Language. Proper names and terms for which there are no signs are usually fingerspelled. In the educational setting, the use of fingerspelling as the primary mode of communication in combination with spoken English is known as the Rochester method.

Manual English

When the vocabulary of the American Sign Language and fingerspelled words are presented in English word order, a 'pidgin' results. Pidgin Sign En-

glish (PSE) is neither strictly English nor ASL, but combines elements of both.

A number of systems have recently been devised to assist deaf children in learning English. These systems supplement some ASL signs with invented signs that correspond to elements of English words (plurals, prefixes, and suffixes, for example). There is usually a set of rules for word (sign) formation within the particular system. These systems are generically known as manually coded English or manual English systems. The two most commonly used today are Signing Exact English and Signed English. While each of these systems was devised primarily for use by parents and teachers in the educational setting, many of the invented and initialized signs from their lexicons are filtering into the vocabulary of the general deaf community.

Oral Communication

This term denotes the use of speech, residual hearing, and speechreading as the primary means of communication for deaf people.

The application of research findings and technological advances through the years has led to refinements in the rationale for and approach to teaching speech to deaf children. Several findings are pertinent here. Deaf children may actually have functional residual hearing. The speech signal is redundant. Since it carries excess information, it is not necessary to hear every sound to understand a message. For language learning to be successful with deaf children (no matter what the educational approach), programs of early intervention must take place during the critical language-learning years of birth through 6. Hearing screening procedures that accurately detect hearing impairments in very young children make it possible to fit hearing aids and other amplification devices and to introduce auditory and language training programs as soon as the problem is detected.

Almost all auditory approaches today rely heavily on the training of residual hearing. The traditional auditory/oral approach trains the hearing impaired child to acquire language through speechreading (lipreading), augmented by the use of residual hearing, and sometimes vibro-tactile cues. The auditory/verbal approach (also called unisensory or acoupedic method) teaches children to process language through amplified residual hearing, so that language is learned through auditory channels.

Speechreading

Recognizing spoken words by watching the speaker's lips, face, and gestures is a daily challenge for all deaf people. Speechreading is the least consistently visible of the communication choices available to deaf people; only about 30 percent of English sounds are visible on the lips, and 50 percent are homophonous, that is, they look like something else. Try it for yourself. Look in a mirror and 'say' without voice the words 'kite,' 'height,' 'night.' You'll see almost no changes on your lips to distinguish among those three words. Then say the following three words—'maybe,' 'baby,' 'pay me.' They look exactly alike on the lips.

Some deaf people become skilled speechreacers, especially if they can supplement what they see with some hearing. Many do not develop great skill at speechreading, but most deaf people do speechread to some extent. Because speechreading requires guesswork, very few deaf people rely on speechreading alone for exchanges of important information.

Cued Speech

Cued Speech is a system of communication in which eight hand shapes in four possible positions supplement the information visible on the lips. The hand "cue" signals a visual difference between sounds that look alike on the lips—such as /p/, /b/, /m/. These cues enable the hearing impaired person to see the phonetic equivalent of what others hear. It is a speech-based method of communication aimed at taking the guesswork out of speechreading.

Simultaneous Communication

This term denotes the combined use of speech, signs, and fingerspelling. Simultaneous communication offers the benefit of seeing two forms of a message at the same time. The deaf individual speechreads what is being spoken and simultaneously reads the signs and fingerspelling of the speaker.

Total Communication

Total Communication is a philosophy which implies acceptance and use of all possible methods of communication to assist the deaf child in acquiring language and the deaf person in understanding.

Historically, proponents of particular systems have often been at odds with proponents of other systems or modes. There is increasing consensus that whatever system or systems work best for the individual should be used to allow the hearing impaired person access to clear and understandable communication.

Deaf Adults in Today's Society

The deaf adult population in the United States is composed both of individuals deaf since early childhood and individuals who lost their hearing later in life. People who were deafened as adults, or after the age of 18, are sometimes called post-vocationally deaf. Having already embarked on their careers, these people may have serious problems both personally and professionally adjusting to their hearing loss. People who were deafened prior to age 18 may have problems not only with English language skills, but also, because of fewer opportunities for interaction with hearing people in pre-work settings, they may be less well prepared for interpersonal relationships they encounter in the job market.

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Educational Institutions

Schools for deaf students have traditionally played an important role in advancing the welfare of deaf people through education of deaf students and public information efforts about the capabilities and accomplishments of deaf people. Two national institutions each have enrollments of over 1,000 deaf students.

Gallaudet University
800 Florida Ave. NE
Washington, DC 20002-3625

National Technical Institute for the Deaf
Rochester Institute of Technology
1 Lomb Memorial Drive
Rochester, NY 14623

For descriptions of the more than 100 postsecondary programs for deaf students at community colleges and technical schools around the country, order a copy of **College and Career Programs for Deaf Students** for $12.95 from:

College and Career Programs
Center for Assessment and Demographic Studies
800 Florida Ave. NE
Washington, DC 20002-3625

Special Devices for Deaf People

Technology and inventiveness have lead to a number of devices which aid deaf people and increase convenience in their daily lives. Many of these devices are commercially available under different trade names.

Telecommunications Devices for Deaf People (TDDs) are mechanical/electronic devices which enable people to type phone messages over the telephone network. The term TDD is generic and replaces the earlier term TTY which refers specifically to teletypewriter machines. Telecaption adapters, sometimes called decoders, are devices which are either added to existing television sets or built into certain new sets to enable viewers to read dialogue and narrative as captions (subtitles) on the TV screen. These captions are not visible without such adapters.

Signalling Devices which add a flashing and/or vibrating signal to the existing auditory signal are popular with hearing impaired users. Among devices using flashing light signals are door "bells," telephone ring signallers, baby-cry signals (which alert the parent that the baby is crying), and smoke alarm systems. Alarm clocks may feature either the flashing light or vibrating signal.

Some Special Services

Numerous social service agencies extend their program services to deaf clients. In addition, various agencies and organizations—either related to deafness or to disability in general—provide specific services to deaf people. Among these special services are the following:

Captioned Films for the Deaf
A loan service of theatrical and educational films captioned for deaf viewers. Captioned Films for the Deaf is one of the projects funded by the Captioning and Adaptations Branch of the U.S. Department of Education to promote the education and welfare of deaf people through the use of media. This branch also provides funds for closed-captioned television programs, including the live-captioned ABC-TV news.

Registry of Interpreters for the Deaf, Inc.
A professional organization, RID maintains a national listing of individuals skilled in the use of American Sign Language and other sign systems and provides information on interpreting and evaluation and certification of interpreters for deaf people.

State Departments of Vocational Rehabilitation
Each state has specific provisions for the type and extent of vocational rehabilitation service, but all provide vocational evaluation, financial assistance for education and training, and job placement help.

Telecommunications for the Deaf, Inc.
TDI publishes an international telephone directory of individuals and organizations who own and maintain TDDs (telecommunications devices for deaf people) for personal or business use.

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Discrimination is a common problem for minority groups. Deaf people as members of a minority group, experience their share of discrimination. Deaf people as a group are underemployed. Together with members of other minority and disabled groups, deaf people are working to change attitudes which have given them jobs but inadequate advancement opportunities.

In the United States, deaf people work in almost every occupational field. Some have become doctors, dentists, lawyers, and members of the clergy. A number of deaf people enter careers within the field of deafness. Thirteen hundred teachers of deaf students in the United States are themselves hearing impaired individuals. In addition, there are deaf administrators, psychologists, social workers, counselors, and vocational rehabilitation specialists. Deaf people drive cars and hold noncommercial pilot's licenses and pursue the same leisure time interests as everyone else.

Many deaf young people have attended school with deaf classmates. This educational pattern, coupled with ease of communication and compatibility encouraged by shared experiences as deaf individuals, leads to socializing with other deaf individuals in maturity. Many deaf people (80 percent) tend to marry other deaf people; most of their children (approximately 90 percent) are hearing.

The Deaf Community

Because the problem in dealing with the hearing world is one of communication, deaf people tend to socialize together more than do people with other disabilities. However, members of the deaf community have contacts with other people, too. Some are active members of organizations of hearing people. Some deaf people move freely between hearing and deaf groups, while other deaf people may have almost no social contact with hearing people. A few deaf people may choose to socialize only with hearing people.

While it is possible to find deaf individuals in every section of the United States, there are major concentrations of deaf people in the larger metropolitan areas of the East and West coasts.

Organizations of and for Deaf People

Clubs and organizations of deaf people range in purpose from those with social motives (watching captioned films, for example) to those with charitable aims. Organizations offer deaf people the opportunity to pursue a hobby (athletics, drama) or civic commitment (political action) on the local, regional or national level. Local or state associations of deaf people may be affiliated with the National Association of the Deaf. The Oral Deaf Adults Section of the Alexander Graham Bell Association for the Deaf has local chapters that provide social opportunities for deaf people who favor oral communication. The National Fraternal Society of the Deaf provides insurance and supports social and charitable functions. It has 120 divisions throughout the United States and Canada.

A few of the more than 20 national organizations of and for deaf people in the United States are briefly described in the following list. Many of these organizations publish newsletters, magazines, or journals. Add to these the publications developed by clubs and schools for the deaf (for students and alumni) and it is possible to identify 400 publications aimed at a readership within the deaf community.

Alexander Graham Bell Association for the Deaf
3417 Volta Place, NW
Washington, DC 20007
(202) 227-5220 (V/TDD)

A private, nonprofit organization serving as an information resource, advocate, publisher, and conference organizer, the Alexander Graham Bell Association is committed to finding more effective ways of teaching deaf and hard of hearing people to communicate orally. Sections within the organization focus on the needs of deaf adults (Oral Deaf Adults Section) and parents (International Parent Organization).

American Deafness and Rehabilitation Association
P.O. Box 55369
Little Rock, AR 77225
(501) 663-4617 (V/TDD)

An interdisciplinary organization for professional and lay persons concerned with services to adult deaf people, ADARA sponsors workshops for state rehabilitation coordinators.

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400 (V/TDD)

Composed of parents and concerned professionals, ASDC provides information, organizes conventions, and offers training to parents and families with children who are hearing impaired.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788 (V/TDD)

With 50 state association affiliates and an aggregate membership exceeding 20,000, the NAD is a consumer advocate organization concerned about and involved with every area of interest affecting life opportunities for deaf people. It serves as a clearinghouse of information on deafness, offers for sale over 20 books on various aspects of deafness, and works cooperatively with other organizations representing both deafness and other disabilities on matters of common concern.

Suggested Readings

Davis, H. and Silverman, R.S., (1978). ***Hearing and Deafness*** (4th ed.) New York: Holt, Rinehart and Winston.

Freeman, R., Carbin, C.F. and Boese, R., (1981). ***Can't Your Child Hear? A Guide for Those Who Care About Deaf Children.*** Baltimore: University Park Press.

Gannon, J., (1981). ***Deaf Heritage.*** Silver Spring, MD: National Association of the Deaf.

Katz, L., Mathis, S.; and Merrill, E.C. Jr., (1978). ***The Deaf Child in the Public Schools: A Handbook for Parents of Deaf Children*** (2nd ed.). Danville, IL: Interstate Printers and Publishers.

Mindel, E.; and Vernon, M., (1971). ***They Grow in Silence: The Deaf Child and his Family.*** Silver Spring, MD: National Association of the Deaf.

Moores, D., (1987). ***Educating the Deaf: Psychology, Principles, and Practices*** (3rd ed.). Boston: Houghton Mifflin Co.

Ogden,P.; and Lipsett, S.,(1982). ***The Silent Garden: Understanding the Hearing Impaired Child.*** New York City: St. Martin's Press.

Schlesinger, H.; and Meadow, K. (1974). ***Sound and Sign: Childhood Deafness and Mental Health.*** Berkeley: University of California.

Spradley, T.S.; and Spradley, J.P. (1978). ***Deaf Like Me.*** Washington, DC: Gallaudet University Press.

Directory of Services

The April issue of the ***American Annals of the Deaf*** is a directory of the various programs and services for deaf persons in the United States. Copies of this reference may be purchased from:

American Annals of the Deaf
Gallaudet University
KDES, PAS 6
800 Florida Ave. NE
Washington, DC 20002-3625

Additional Information

If you have specific questions that were not answered by this fact sheet, please contact either the National Information Center on Deafness, Gallaudet University, Washington, DC 20002, or the National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910.

The National Information Center on Deafness (NICD) is a centralized source of information on all aspects of deafness and hearing loss, including education of deaf children, hearing loss and aging, careers in the field of deafness, assistive devices and communication with hearing impaired people.

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

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HEARING DISABILITIES

THINGS TO KNOW:

- There are more people who are partially deaf than have no hearing at all.
- Sign language is not another form of English. It is an official language with its own grammar, context and rules.
- Lip-reading, while helpful without sound clues, is only 30% - 50% effective and can be very tiring after long conversations.

THINGS TO DO: COMMUNICATING

- Find out how the person best communicates.
- Gain their attention *before* starting a conversation.
- If the person uses an interpreter, address the person, not the interpreter.
- Use a pencil and paper to communicate your thoughts.
- Body language is important. Try to match your facial expressions and body language with what you are saying. For example, if you're angry and saying angry words, show that anger on your face.

Continued ...

IF THE PERSON LIP-READS . . .

- Speak in a normal, unexaggerated manner. Simple, short sentences are best.
- Be patient if you are asked to repeat yourself.
- It is important that there are no physical barriers between yourself and the person with whom you are speaking. Good lighting is also helpful.

THINGS TO CONSIDER

- People who are deaf may have difficulty communicating when there are two or more speakers, especially if there are many interruptions and background noises. Try to keep the conversations clear and move to a quiet setting if possible.
- If you are asked to repeat yourself, be patient and comply. Answering *"Never mind"* or *"Nothing, it's not important"* is demeaning to the person who's deaf. These responses imply the person is not worth repeating yourself for.

TELECOMMUNICATION DEVICE FOR THE DEAF

This telephone device uses a keyboard and a digital readout screen to provide communication between people who are deaf and whatever source has a TDD on the other end. These devices are relatively easy accommodations to make and can dramatically enhance the lifestyle and working potential of the person who is deaf.

The Americans With Disabilities Act now requires every state to provide free TDD relay services. This enables two people to communicate even when a TDD is not available at both ends.

MISCONCEPTIONS ABOUT PERSONS WITH HEARING IMPAIRMENTS

MYTH > Deafness is not as severe a disability as blindness.	**FACT >** Although it is impossible to predict the exact consequences of a disability on a person's functioning, in general, deafness poses more difficulties in adjustment than does blindness. This is largely due to the effects hearing loss can have on the ability to understand and speak oral language.
MYTH > It is unhealthy for people who are deaf to socialize almost exclusively with others who are deaf.	**FACT >** Many authorities now recognize that the phenomenon of a Deaf culture is natural and should be encouraged. In fact, some are worried that too much mainstreaming will diminish the influence of the Deaf culture.
MYTH > In learning to understand what is being said to them, people with hearing impairment concentrate on reading lips.	**FACT >** *Lipreading* refers only to visual cues arising from movement of the lips. Some people who are hearing impaired not only read lips, but also take advantage of a number of other visual cues, such as facial expressions and movements of the jaw and tongue. They are engaging in what is referred to as *speechreading*.
MYTH > Speechreading is relatively easy to learn and is used by the majority of people with hearing impairment.	**FACT >** Speechreading is extremely difficult to learn, and very few people who are hearing impaired actually become proficient speechreaders.
MYTH > American Sign Language (ASL) is a loosely structured group of gestures.	**FACT >** ASL is a true language in its own right with its own set of grammatical rules.
MYTH > ASL can convey only concrete ideas.	**FACT >** ASL can convey any level of abstraction.
MYTH > People within the Deaf community are in favor of mainstreaming students who are deaf into regular classes.	**FACT >** Some within the Deaf community have voiced the opinion that regular classes are not appropriate for many students who are deaf. They point to a need for a critical mass of students who are deaf in order to have effective educational programs.
MYTH > Families in which both the child and the parents are deaf are at a distinct disadvantage compared to families in which the parents are hearing.	**FACT >** Research has demonstrated that children who are deaf who have parents who are also deaf fare better in a number of academic and social areas. Authorities point to the parents' ability to communicate with their children in ASL as a major reason for this advantage.

Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 303.

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Deaf pitcher doesn't let disability stand in way of success

Hitters and pitchers look for them. Catchers and coaches give them. Everyone tries to steal them. Signs are as much a part of the game of baseball as the bat and ball.

And in a society that does not always accommodate the hearing impaired, baseball—with its endless parade of signs and gestures—is an oasis where the hearing and deaf alike attend on equal footing.

Aaron Farley is deaf. He also happens to have been raised on baseball. The name given at birth—Aaron (as in Hank) Matthew (as in Eddie, only without the 's') Farley (as in Aaron's father Bob, big Braves' fan)—left little doubt that baseball would constitute a huge part of his life.

Make no mistake about it, when Farley takes the mound in this weekend's 17-18 year old Babe Ruth state tournament in Purcellville, the 18-year-old C.B. Baker all-star will be just another baseball player.

"Baseball is one of those beautiful sports that rely so much on symbols," said Bob Farley, who also serves as all-star coach. "When the game starts we all speak a different language, anyway."

If baseball is unique in that sense, then it owes a good deal to deaf individuals such as William Hoy. An act so central to the national pastime—the umpire's animated strike call—was prompted by Hoy, a turn-of-the-century National League outfielder, who required hand signals to know if the pitch was a ball or a strike.

The symbolic code that has developed in the years since is a language Farley probably understands better than most.

Born profoundly deaf—the most severe degree of hearing impairment—Farley is capable of hearing high-decibel sounds like thunder, but little else. So he compensates with eyes. Farley confidently states that no one on the playing field sees as much as he does. His father doesn't remember him ever missing a sign.

His own safety, in fact, requires that Farley rigidly adhere to the proverbial command—keep your eye on the ball.

"He has to focus and concentrate on the entire game," said the elder Farley. "I don't know if it makes him better, but it sure makes him tired."

Moreover, it makes him intensely competitive. As one not distracted on the field, he expects nothing less from his teammates. "I don't want to make a mistake, I don't want my teammates to make a mistake," Aaron said. "I want to win."

Win he has. During the C.B. Baker regular season, Farley posted a perfect 4-0 record for champion Puritan, the best mark in the league. He was equally successful at the plate with a .360 batting average.

PROGRESS PHOTO BY MATT GENTRY

Aaron Farley of the C. B. Baker League All-Star team has not let deafness keep him from enjoying success as a pitcher. The 18-year-old is 6–0 this summer (1992) in regular season and tournament play.

In last weekend's District 5 tournament, Farley added two more wins—including Sunday's 12-6 championship victory—to help put the Charlottesville squad in today's first-round game against the District 7 champions.

On the subject of stats, try this one: 3.60. Not ERA, but GPA. In June, Farley graduated with honors from Charlottesville High School and will attend Rochester (N.Y.) Institute of Technology this fall with plans to major in computer science and math.

A message blackboard in Farley's bedroom frequently carries this admonition from his father: "Most limitations are self-imposed." The son has taken the saying to heart. Consequently, Aaron Farley has not allowed his disability to get in the way of on- or off-field achievement.

He rejects the notion, however, that he is any sort of role model, but the message is clear: Being deaf is no excuse not to participate, or succeed.

SOURCE: The Daily Progress, July, 17, 1992, pp. C1, C2.
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Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 11.

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XIII. Speech and Language Disorders

- General Information about Speech and Language Disorders (NICHCY Fact Sheet)
- Misconceptions about Persons with Communication Disorders
- The Manual Alphabet
- Practice Learning Signs

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NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free) (202) 416-0300 (Local, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

General Information About

SPEECH AND LANGUAGE DISORDERS

Definition

Speech and language disorders refer to problems in communication and related areas such as oral motor function. These delays and disorders range from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech and feeding. Some causes of speech and language disorders include hearing loss, neurological disorders, brain injury, mental retardation, drug abuse, physical impairments such as cleft lip or palate, and vocal abuse or misuse. Frequently, however, the cause is unknown.

Incidence

One quarter of the students served in the public schools' special education programs (almost 1 million children in the 1988-89 school year) were categorized as speech or language impaired. This estimate does not include children who have speech/language problems secondary to other conditions such as deafness. Language disorders may be related to other disabilities such as mental retardation, autism, or cerebral palsy. It is estimated that communication disorders (including speech, language, and hearing disorders) affect one of every 10 people in the United States.

Characteristics

A child's communication is considered delayed when the child is noticeably behind his or her peers in the acquisition of speech and/or language skills. Sometimes a child will have greater receptive (understanding) than expressive (speaking) language skills, but this is not always the case.

Speech disorders refer to difficulties producing speech sounds or problems with voice quality. They might be characterized by an interruption in the flow or rhythm of speech, such as stuttering, which is called dysfluency. Speech disorders may be problems with the way sounds are formed, called articulation or phonological disorders, or they may be difficulties with the pitch, volume, or quality of the voice. There may be a combination of several problems. People with speech disorders have trouble using some speech sounds, which can also be a symptom of a delay. They may say "see" when they mean "ski" or they may have trouble using other sounds like "l" or "r". Listeners may have trouble understanding what someone with a speech disorder is trying to say. People with voice disorders may have trouble with the way their voices sound.

A language disorder is an impairment in the ability to understand and/or use words in context, both verbally and nonverbally. Some characteristics of language disorders include improper use of words and their meanings, inability to express ideas, inappropriate grammatical patterns, reduced vocabulary, and inability to follow directions. One or a combination of these characteristics may occur in children who are affected by language learning disabilities or developmental language delay. Children may hear or see a word but not be able to understand its meaning. They may have trouble getting others to understand what they are trying to communicate.

Educational Implications

Because all communication disorders carry the potential to isolate individuals from their social and educational surroundings, it is essential to find appropriate timely intervention. While many speech and language patterns can be called "baby talk" and are part of a young child's normal development, they can become problems if they are not outgrown as expected. In this way an initial delay in speech and language or an initial speech pattern can become a disorder which can cause difficulties in learning. Because of the way the brain develops, it is easier to learn language and communication skills before the age of 5. When children have muscular disorders, hearing problems or developmental delays, their acquisition of speech, language, and related skills is often affected.

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Speech-language pathologists assist children who have communication disorders in various ways. They provide individual therapy for the child; consult with the child's [illegible]r about the most effective ways to facilitate the [illegible]s communication in the class setting; and work closely with the family to develop goals and techniques for effective therapy in class and at home. Technology can help children whose physical conditions make communication difficult. The use of electronic communication systems allow nonspeaking people and people with severe physical disabilities to engage in the give and take of shared thought.

Vocabulary and concept growth continues during the years children are in school. Reading and writing are taught and, as students get older, the understanding and use of language becomes more complex. Communication skills are at the heart of the education experience. Speech and/or language therapy may continue throughout a student's school year either in the form of direct therapy or on a consultant basis. The speech-language pathologist may assist vocational teachers and counselors in establishing communication goals related to the work experiences of students and suggest strategies that are effective for the important transition from school to employment and adult life.

Communication ha[illegible] many components. All serve to [illegible]crease the way people learn about the world around them, utilize knowledge and skills, and interact with colleagues, family, and friends.

Resources

Bernthal, J.E. & Bankson, N.W. (1993). *Articulation and phonological disorders* (3rd ed). Englewood Cliffs, NJ: Prentice Hall. (Telephone: 1-800-947-7700.)

Beukelman, D.R., & Mirenda, P. (1992). *Augmentative and alternative communication: Management of severe communication disorders in children and adults.* Baltimore, MD: Paul H. Brookes. (Telephone: 1-800-638-3775.)

Shames, G.H., & Wiig, E.H. (1990). *Human communication disorders: An introduction* (3rd ed.). Columbus, OH: Merrill. (Contact Macmillan Publishing at 1-800-257-5755.)

Organizations

Alliance for Technology Access
1128 Solano Avenue
Albany, CA 94706
(510) 528-0747

Cleft Palate Foundation
1218 Grandview Ave.
University of Pittsburgh
Pittsburgh, PA 15211
412-481-1376; 800-242-5338; 800-243-5338 (in PA)

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
301-897-5700 (V/TT); 800-638-8255

Learning Disabilities Association of America (LDA)
4156 Library Road
Pittsburgh, PA 15234
412-341-1515; 412-341-8077

Division for Children with Communication Disorders
c/o Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091-1589
703-620-3660

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
312-726-6200; 312-726-4258 (TT)
800-221-6827 (Calls outside IL)
(For information about services for children and youth.)

Scottish Rite Foundation
Southern Jurisdiction, U.S.A., Inc.
1733 Sixteenth Street, N.W.
Washington, DC 20009-3199
202-232-3579

Trace Research and Development Center
University of Wisconsin - Madison
S-151 Waisman Center
Madison, WI 53705-2280
608-262-6966; 608-263-5408 (TT)

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SPEECH DISABILITIES

There are many things which can cause difficulty with speech. Deafness, cerebral palsy, stroke, head injury and general speech impairment are just a few. The following suggestions may help you communicate more effectively with someone who has a speech disability.

THINGS TO CONSIDER:

- Many people with speech disabilities are mistakenly identified as being drunk, retarded or mentally ill. Communicating with them may simply require patience and finding out what works best.

THINGS TO DO:

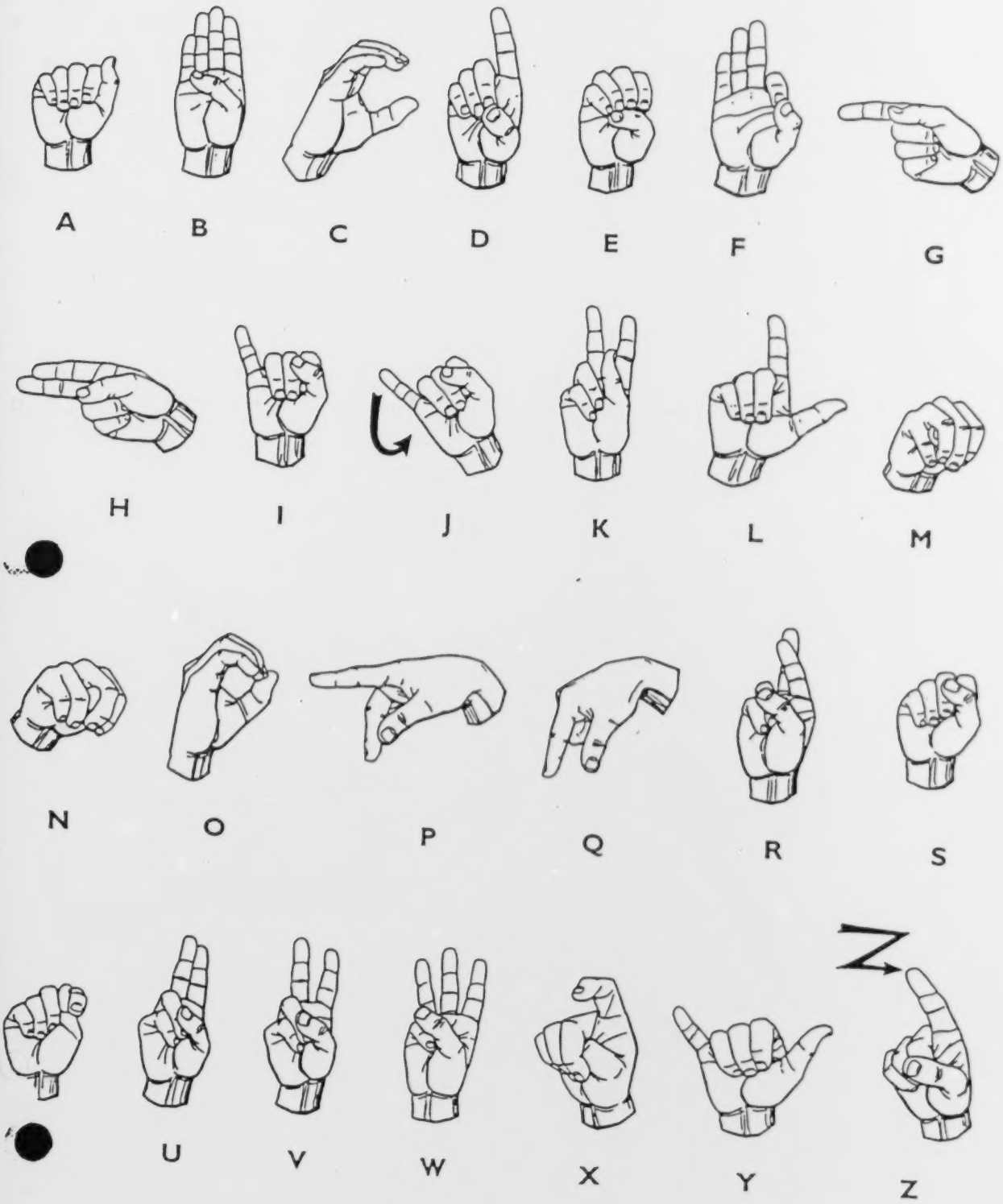
- Give whole, unhurried attention when you're talking to someone who has difficulty speaking. If you're having trouble understanding the person, ask them to repeat themselves rather than pretending you understand.
- If you're trying to communicate in a public area with many distractions, stay calm and try to move to a quieter location.
- Keep your manner encouraging rather than correcting. Be patient and don't speak for people. Let them complete their own sentences.
- When necessary, ask short questions that require short answers (or a nod, or shake of the head).
- Use writing as an alternative form of communication.

MISCONCEPTIONS ABOUT PERSONS WITH COMMUNICATION DISORDERS

MYTH > Children with language disorders always have speech difficulties as well.	**FACT** > It is possible for a child to have good speech and yet not make any sense when he or she talks; however, most children with language disorders have speech disorders as well.
MYTH > Individuals with communication disorders always have emotional or behavioral disorders or mental retardation.	**FACT** > Some children with communication disorders are normal in cognitive, social, and emotional development.
MYTH > How children learn language is now well understood.	**FACT** > Although recent research has revealed quite a lot about the sequence of language acquisition and has led to theories of language development, exactly how children learn language is still unknown.
MYTH > Stuttering is primarily a disorder of people with extremely high IQs. Children who stutter become stuttering adults.	**FACT** > Stuttering can affect individuals at any level of intellectual ability. Some children who stutter continue stuttering as adults; most, however, stop stuttering before or during adolescence with help from a speech-language pathologist. Stuttering is primarily a childhood disorder, found much more often in boys than in girls.
MYTH > Disorders of phonology (or articulation) are never very serious and are always easy to correct.	**FACT** > Disorders of phonology can make speech unintelligible; it is sometimes very difficult to correct phonological or articulation problems, especially if the individual has cerebral palsy, mental retardation, or emotional or behavioral disorders.
MYTH > A child with a cleft palate always has defective speech.	**FACT** > The child born with a cleft palate may or may not have a speech disorder, depending on the nature of the cleft, the medical treatment given, and other factors such as psychological characteristics and speech training.
MYTH > There is no relationship between intelligence and disorders of communication.	**FACT** > Communication disorders tend to occur more frequently among individuals of lower intellectual ability, although these disorders may occur in individuals who are extremely intelligent.
MYTH > There is not much overlap between language disorders and learning disabilities.	**FACT** > Problems with verbal skills—listening, reading, writing, speaking—are often a central feature of a learning disability. The definitions of language disorders and several other disabilities are overlapping.

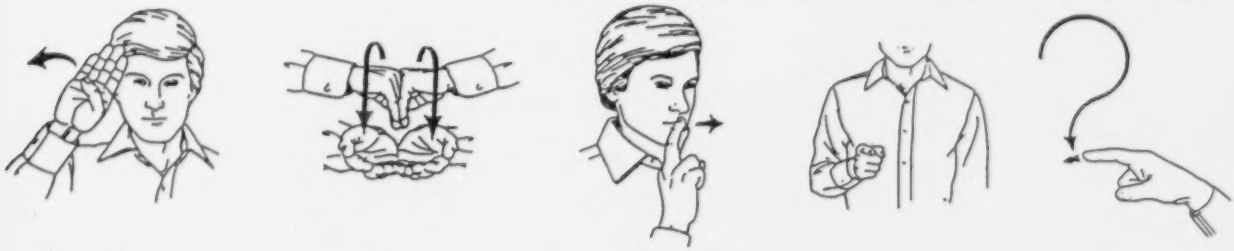
Hallahan, D.P., & Kauffman, J.M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 255.

The Manual Alphabet

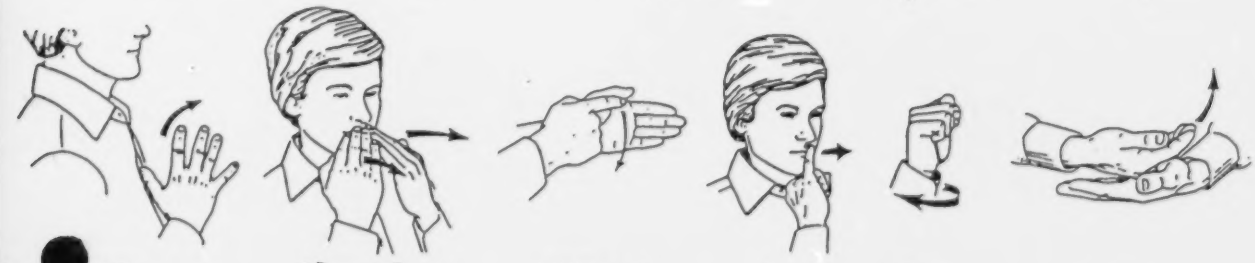


Practice Learning Signs

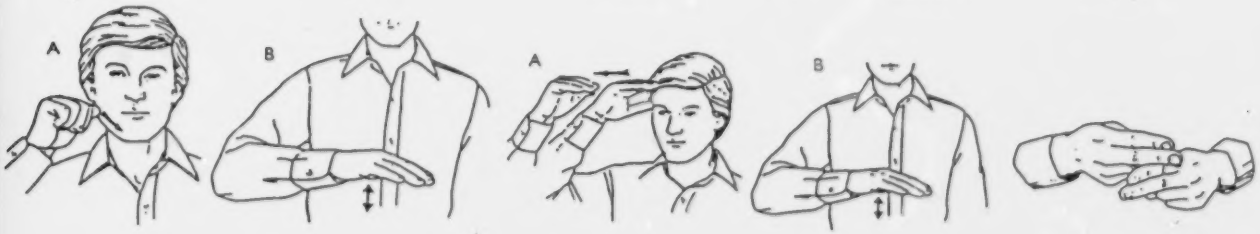
Learn and practice the signs and sentences on each page before proceeding to the next. Descriptions are supplied at the bottom of each page.



Hi, how are you ?



Fine, thanks. What is the new



girl's / boy's / name?

XIV. Autism

- General Information about Autism (NICHCY Fact Sheet)
- Common Misconceptions about Persons with Autism
- Autism Fact Sheet
- Autism, Mark Reber
- Facts about Autism
- Self Injury, Answers to Questions for Parents, Teachers and Caregivers

NICHCY

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SpecialNet User Name: NICHCY •• SCAN User Name: NICHCY

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

General Information About

AUTISM

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

✧ Definition ✧

Autism is a developmental disorder which usually becomes evident before the age of three years. It is a neurological or brain disorder in which behavior, communication, and social interactions are the primary disabilities.

✧ Incidence ✧

The rate of incidence, or how often autism occurs in children, ranges from five to fifteen out of 10,000 births. The different estimates are based on slightly different definitions of autism.

It is three times more common in boys than girls and is rarely found in more than one child in a family.

Autism can be caused by a number of factors, but the cause in the vast majority is not known. It is known that autism is caused by biological, not psychological, factors.

✧ Characteristics ✧

Some babies show signs of autism from infancy. They may not like to cuddle and may show little interest in their families.

Typical characteristics of autism are often described as:

- difficulty relating to people, objects and events;
- repetitive movements such as rocking and spinning, head banging and hand twisting;
- insistence that the environment and routine remain unchanged;
- avoidance of eye contact;
- verbal and nonverbal communication skills are severely impaired;
- use of toys and objects is an unconventional manner, little imaginative play;
- severe impairment of social interaction development; and
- limited intellectual ability.

It should be noted that any one of these characteristics may occur in children with other disabilities. In these cases the term "autistic-like" behavior is used.

✧ Educational Implications ✧

Early diagnosis and educational evaluation of autism are very important, although help given at any age can make a significant difference.

Public Law 101-476, the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act, now includes autism as a separate disability category. Children with autism will be eligible for special education and related services under this new category.

Until recently, children with autism have been eligible for special education and related

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services under the category of "other health impaired." The regulations (CFR 300.5) to the Education of the Handicapped Act state, "Other health impaired means (i) having an autistic condition which is manifested by severe communication and other developmental and educational problems...". These regulations will be changed to reflect autism as a category included under the IDEA.

Emphasis in education needs to be on helping the child to learn ways to communicate and on structuring the environment so that it is consistent and predictable. Effective teaching includes attention to behavior plans, positive behavior management, and clear expectations and rules.

Many of these methods can be developed in conjunction with parents and followed through at home. Continuity and consistency between home and school environments can greatly aid in the security and progress of persons with autism.

While autism is a lifetime condition, with special training, supervision, and support, many adults with autism can live and work in the community.

✧ Resources ✧

Autism Research International Newsletter
Institute for Child Behavior Research
4182 Adams Avenue
San Diego, CA 92116

Journal of Autism and Developmental Disorders
Plenum Publishing Corporation
233 Spring Street
New York, NY 10013

Park, Clara, (1982) *The Siege*. Boston; Little Brown and Company.

Powers, Michael D. (Ed) (1989). *Children with Autism, A Parent's Guide*. Rockville, MD; Woodbine House.

Wing, L., M.D., (1980). *Autistic Children: A Guide for Parents and Professionals*. Secaucus, NJ: The Citadel Press.

✧ Organizations ✧

Autism Hotline
Autism Services Center
101 Richmond Street
Huntington, WV 25702
(304) 523-8269

Autism Society of America
8601 Georgia Avenue
Suite 503
Silver Spring, MD 20910
(301) 565-0433

Institute for Child Behavior Research
4182 Adams Avenue
San Diego, CA 92116
(618) 281-7165

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For more information contact NICHCY.

Common Misconceptions About Autism

Misconceptions	Facts
1. Autism is an emotional disorder	Autism occurs as a result of diverse organic etiologies
2. It is difficult to distinguish between autism and childhood schizophrenia	Autism and schizophrenia differ on several important features, including age of onset, cognitive level, course, and family history
3. Autism occurs more commonly among higher SES and educational levels	Autism appears to be evenly distributed across all SES and educational levels
4. Autism exists only in childhood	Autism is a lifelong disorder
5. With the proper treatment, most autistic children eventually "outgrow" autism	Characteristics and behaviors associated with autism often improve as a result of intervention
6. Autistic children do not show social attachments, even to parents	Autistic children can and do form social attachments, though their relationships typically lack a sense of reciprocity
7. Autistic children do not show affectionate behavior	Autistic children can and do show affectionate behaviors such as hugging and kissing
8. Most autistic children have special talents or abilities	Many autistic children have unevenly developed cognitive skills, but very few have savant capabilities
9. Most autistic children are not mentally retarded	70% - 80% of autistic children function intellectually within the range of mental retardation
10. Autistic children are more intelligent than scores from appropriate tests indicate	I.Q. scores are accurate, stable, and predictive when appropriate instruments and assessment strategies are used

W. Stone, Ph.D.
6/94

Is there a voluntary agency for autism?

Yes, The Autism Society of America, Inc. is the only national agency dedicated to the education and welfare of people with autism. Its priorities are research and education. More than 200 chapters exist across the United States. The Society's national office address is:

Autism Society of America
7910 Woodmont Avenue • Suite 650
Bethesda, Maryland 20814-3015
(301) 657-0881 • Fax: (301) 657-0869

*Formerly NSAC, The National Society for Children and Adults With Autism

How can I learn more?

The information and Referral Service at the Autism Society of America, Inc. can provide reading lists and film lists, and will answer questions. Following are some recommended publications, which can be obtained through our national office along with a comprehensive list of other appropriate references.

Advocate, Autism Society of America, A Collection of Writings from *Advocate*, 1979-1989, Compiled by Beth Sposato, Lincoln Nebraska.

Alternatives to Punishment, Donnellan and LaVigna, Irvington Publishers, Inc., 1986

Autistic Children, A Guide for Parents and Professionals, Wing, Citadel Press, 1972

Biology of the Autistic Syndomes, Mary Coleman, et al. Amsterdam, North Holland Publishing Company, 1976.

Children With Autism, Edited by Powers, 1989

Classic Readings in Autism, compiled by Ann Donnellan, New York, Teachers College Press, 1985

Current Issues in Autism Series, Edited by Schopler and Mesibov, Plenum Press

Emergence Labled Autistic, Grandin, Arena Press, 1986

Gentle Teaching, McGee, Menolascino, Hobba, Menousek, Human Sciences Press, Inc., 1987

Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior, Rimland, 1964

Mixed Blessings, Christopher and Christopher, Abingdon Press, 1989

The Siege, Park, Boston: Little Brown & Co. 1982

Note: Much of the information in this leaflet is taken from the Short Definition of Autism, adopted by the Professional Advisory Board and the Board of Directors of the Autism Society of America, Inc., June 27 1977.

AUTISM:

Not responsive to normal teaching methods
Inappropriate laughing and giggling
No understanding of real dangers
Apparent insensitivity to pain
Resistant to being cuddled
Sustained unusual or repetitive play uneven physical verbal skills
Avoids eye contact
Stand offish manner
Difficulty in expressing needs. May use gestures
Inappropriate attachments to objects
ARE YOU GOING?
Echoes words and phrases
Inappropriate response, or no response, to sound
Crying tantrums
Extreme distress for no discernible reason
Spins objects or self
Does not mix well with other children
Resists changes in routine
Physically overactive or passive

NOTE: persons with autism may possess the above characteristics in various combinations and in varying degrees of severity.

Autism Society of America
7910 Woodmont Avenue • Suite 650
Bethesda, Maryland 20814-3015
(301) 657-0881 • Fax: (301) 657-0869

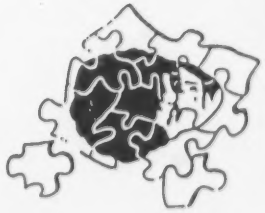
*Formerly NSAC, The National Society for Children and Adults With Autism

Prepared by
Office of Scientific and Health Reports
National Institute of Neurological and
Communicative Disorders and Stroke
Bethesda, Maryland 20205

NIH Publication No. 83-1877
Reprinted February 1983, 1987, 1990, 1991

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
National Institutes of Health

FACT SHEET: autism



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What [illegible]ism?

Autism is a severely incapacitating, lifelong developmental disability that begins at birth or during the first 3 years of life. It occurs in approximately 5 of every 10,000 births. The incidence is three times greater if a broader definition of autism is used. In the broader category would be both people with classical autism and others with varying degrees of autistic behavior. Autism is three times more common in males than females, and has been found throughout the world in families of all racial, ethnic, and social backgrounds.

What are the symptoms of autism?

- Slow development or lack of physical, social, and learning skills.
- Immature rhythms of speech, limited understanding of ideas, and use of words without attaching the usual meaning to them.
- Abnormal responses to sensations. Sight hearing, touch, pain, balance, smell, taste, the way a child holds his body—any one or a combination of these responses may be affected. (See illustrations on back panel)
- Abnormal ways of relating to people, objects and events.

Approximately 60% of all those with autism have I.Q. scores below 50; 20% between 50 and 70; and 20% greater than 70. Most show wide variations in performance on different tests at different times. Many children with autism have distinct skills in music, mathematics, or in using spatial concepts (for example, working jigsaw puzzles), but manifest severe retardation in other areas.

What causes autism?

There appear to be several possible causes, either alone or in combination with others. Among these are untreated phenylketonuria, rubella, celiac disease, and chemical exposure in pregnancy. Biochemical imbalance and genetic predisposition have also emerged as possible causes. No known factors in the psychological [illegible]nment of a child have been shown to [illegible]utism.

How is it diagnosed?

Because there are no medical tests for autism at present, the diagnosis must be based on observations of the child's behavior. Sometimes the process of elimination is the only guide. For older children, whose early symptoms have changed, it may be necessary to interview the parents about the child's early years in order to avoid misdiagnosis.

Is autism ever associated with other disorders?

Autism occurs either by itself or in association with other disorders which affect brain function. Perinatal viral infections, some metabolic disturbances, epilepsy, or mental retardation may result in, or exist in conjunction with autistic behavior.

How severe can autism be?

In milder forms, autism most resembles a learning disability such as childhood aphasia. Usually, however, people with autism are substantially handicapped.

With approximately 3% of those afflicted, severe autism may cause extreme forms of self-injurious, repetitive, highly unusual, and aggressive behavior. The behavior may persist and be very difficult to change, posing a tremendous challenge to those who must manage, treat, and teach individuals with autism.

People with autism live normal life spans. Since certain symptoms may change or even disappear over time, persons with autism should be reevaluated periodically and their treatment adjusted to meet their changing needs.

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What are the most effective treatments?

Various methods of treatment have been tried but no single treatment is effective in all cases. However, appropriate programming, based on individual functioning level and need, is of prime importance. There is no known cure.

Education. Highly stru[illegible] skill-oriented training, tailored to the i[illegible]l, has proven most helpful. Social and lang[illegible]e skills should be developed as much as possible, Thought must also be given to avoiding secondary handicaps, such as loss of muscle tone when inactivity is a problem.

Counseling. Supportive counseling may be helpful for families with members who have autism, just as it is for other families with members who have lifelong disabilities. Physicians can usually advise parents as to counseling services available. Care must be taken to avoid unenlightened counselors who erroneously believe that parental attitudes and behavior cause autism.

Medication/Diet. In the types of autism where metabolic abnormalities can be identified, controlled diet and/or medication can be beneficial. Examples are those whose autism is caused by an excess of uric acid in the blood, or whose autism is aggravated by nutritional imbalances. Also, properly monitored medication to decrease specific symptoms can help some autistic individuals live more satisfactory lives.

What research is being done?

The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) initiated a research section on autism in 1983, and may be contacted directly concerning research initiatives in diagnostic, treatment, educational, habilitative, and evaluative approaches relevant to autism.

NINCDS is continuing to study the 14 autistic children identified in its Collaborative Perinatal Project (a 15-year study of 55,000 pregnancies and the outcomes). This project centers on efforts to identify predictive signs of autism.

Ongoing study is necessary to determine how autism occurs and to identify ways to prevent or alleviate its effects. Basic research in a broad spectrum of scientific disciplines is needed to shed further light on the challenges presented by Autism

Chapter 22

Autism

with Mark Reber

Upon completion of this chapter, the reader will:
—be able to define autism
—understand the characteristics of this disorder
—know how to distinguish autism from other developmental disabilities
—be acquainted with the various intervention approaches to this disorder

---

Like mental retardation, autism is a brain-based developmental disability with multiple causes. Autism differs from mental retardation in that its characteristic feature is not a delay in development, but a series of striking deviations from normal developmental patterns that become apparent by 3 years of age. Autism involves disturbances in cognition, interpersonal communication, social interactions, and behavior (in particular, the presence of obsessional, ritualistic, stereotyped, and rigid behaviors) (American Psychiatric Association, 1987; Cohen, Donnellan, & Paul, 1987; Gillberg, 1990). Deviant development in all of these areas is necessary for a diagnosis of autism, thus giving rise to its classification as a pervasive developmental disorder.

Autism is a rare condition. Studies have determined its prevalence to be about 4 in 10,000 (Lotter, 1966; Ritvo, Freeman, Pingree, et al., 1989), and boys with autism outnumber girls 4:1. There appears to be a genetic component, as a family with one child with autism has about a 9% risk of having a second child with autism (Ritvo, Jorde, Mason-Brothers, et al., 1989).

A HISTORICAL PERSPECTIVE

Despite its rarity, autism has been the focus of considerable research since it was first described in 1943. Dr. Leo Kanner published the first description of what he called "autistic disturbances of affective contact" (Kanner, 1943, p. 217). He identified a group of children who exhibited symptoms that isolated them from their environment

Mark Reber, M.D., is Clinical Assistant Professor of Psychiatry at The University of Pennsylvania School of Medicine, Children's Seashore House, in Philadelphia.

From Children with Disabilities: A Medical primer, Batshaw and Perret.

and had abnormal language or did not speak at all. In his view, the fundamental disturbance in these children was "an inability to relate themselves in the ordinary way to people and situations from the beginning of life" (p. 242). He observed that as infants, these children did not seek to be held, ignored or shut out any social approaches, treated people as objects, and made minimal eye contact. In addition, children with autism required such a sameness in their environment that even a minor change—for example, the repositioning of a chair—threw them into a rage. Among those children who could speak, unusual features of language included parrot-like repetition of phrases, sometimes uttered long after they were heard (delayed echolalia); literalness of usage; and a tendency to repeat pronouns as heard (e.g., using "you" to refer to oneself). Play was repetitive and stereotyped, with little imaginative use of toys and other objects. Kanner noted that the parents of these children tended to be cold and formal in their interpersonal relationships, but speculated that the disorder was an "inborn disturbance" (p. 250).

In the 2 decades after Kanner's description, "cold" and "aloof" parents were increasingly blamed for causing autism. More recently, autism has been viewed as a disturbance that arises early in life and originates in the child's own biology. Controversy still remains, however, over the symptoms that constitute the core features of the disorder. Kanner emphasized the child's inability to relate, while other researchers have suggested that the language disorder, cognitive disturbance, or a certain group of sensory abnormalities is the essential feature. Definition of the fundamental psychological deficit is important, as it will help to direct research toward uncovering the specific brain disturbance that underlies autism.

CHARACTERISTICS OF AUTISM

In order to be diagnosed with autism, a child must meet 8 of the 16 criteria listed in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-III-R*) (American Psychiatric Association, 1987) (Table 22.1). These criteria fall into three broad categories: 1) impairment in reciprocal social interaction, 2) impairment in communication and imaginative activity, and 3) markedly restricted repertoire of activities and interests. While not included in the diagnostic criteria, other behavioral, cognitive, and neurological disturbances are recognized as part of the disorder. The severity of this disorder is based on intellectual and associated deficits. Autism can occur in children with average intelligence, who have severe problems with communication skills, social interactions, and behavior, and in children with mental retardation and stereotypic behaviors (Rapin, 1991).

Social Interactions

Kanner's view that problems with social interactions represent the fundamental problem in autism is also supported by Wing (1988), who has described three types of social interaction impairments: impaired social recognition, communication, and understanding or imagining.

Impaired social recognition, in its mild form, appears as lack of interest in the feelings and thoughts of others and an absence of eye contact. Individuals with severe

Table 22.1. Diagnostic criteria for autism

At least 8 of the following 16 items should be present. The child should exhibit at least two items from Group A, one from Group B, and one from Group C. (The examples are arranged so that those first mentioned are more likely to apply to younger children or children with more severe autism, and the later examples are more likely to apply to older children or children with less severe autism.)

Group A

Qualitative impairment in social interaction as manifested by the following:

1. Marked lack of awareness of the existence of others or their feelings
2. No effort or an abnormal effort to seek comfort at times of distress (e.g., does not come for comfort even when ill, hurt, or tired); seeks comfort in a stereotyped way (e.g., says "cheese, cheese, cheese" whenever hurt)
3. No imitation or impaired imitation (e.g., does not wave bye-bye, does not copy mother's domestic activities, mechanically imitates others' actions out of context)
4. No social play or abnormal social play (e.g., does not actively participate in simple games, prefers solitary play activities, involves other children in play only as "mechanical aids")
5. Gross impairment in ability to make peer friendships (e.g., no interest in making peer friendships; lacks understanding of conventions of social interaction [e.g., reads telephone book to uninterested peer])

Group B

Qualitative impairment in verbal and nonverbal communication and in imaginative activity as manifested by the following:

1. No mode of communication
2. Markedly abnormal nonverbal communication (e.g., does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, stares fixedly in social situations)
3. Absence of imaginative activity (e.g., no playacting of adult roles, fantasy characters, or animals; lack of interest in stories about imaginary events)
4. Marked abnormalities in speech production, including volume, pitch, stress, rate, rhythm, and intonation (e.g., monotonous tone, question-like melody, high pitch)
5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (e.g., immediate echolalia, mechanical repetition of television commercial); use of "you" when "I" is meant (e.g., using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (e.g., "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (e.g., starts talking about train schedules during a conversation about sports)
6. Markedly impaired ability to initiate or sustain conversations with others, despite adequate speech (e.g., lengthy monologues on one subject regardless of interjections from others)

Group C

Markedly restricted repertoire of activities and interests as manifested by the following:

1. Stereotyped body movements (e.g., hand flicking, hand twisting, spinning, head banging, complex whole-body movements)
2. Persistent preoccupation with parts of objects (e.g., sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (e.g., insists on carrying around a piece of string)
3. Marked distress over changes in trivial aspects of environment (e.g., when a vase is moved from usual position)
4. Unreasonable insistence on following routines in precise detail (e.g., insisting that exactly the same route be followed when shopping)
5. Markedly restricted range of interests and a preoccupation with one narrow interest (e.g., aligning objects, amassing facts about meteorology, pretending to be a fantasy character)

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autism demonstrate extreme aloofness and total indifference to other people. The second component, impaired social communication, is characterized by an absence of pleasure in the exchange of smiles and feelings (i.e., body language). This characteristic may be obvious as early as the first 2–3 months of life, though it often goes unrecognized until other deficits become more obvious (Stone, Lemanek, Fishel, et al., 1990). Impaired social communication also implies a lack of desire to communicate with others or communication that is limited to the simple expression of needs. The third component, impaired social imagination and understanding, refers to the inability to imitate others and engage in pretend play or to imagine another's thoughts and feelings. For example, infants with this deficit do not copy their mothers' facial expressions.

Other social deficits associated with autism include not seeking comfort when hurt and lacking interest in forming friendships. It is unclear whether children with autism do not display normal attachment behavior or do not understand relationships and want to form them (Hertzig, Snow, & Sherman, 1989; Shapiro, Frosch, & Arnold, 1987; Sigman & Mundy, 1989).

Communication Disorders

In children with autism, the development of language is severely delayed and deviant, hindering both expressive and receptive communication (Ferrari, 1982). Cooing and babbling may develop normally in the first 6 months of life, but then may regress. Speech may develop late or not at all. About half of children with autism remain mute throughout their lives and may even be unable to use gestures or signs to communicate (Rutter, 1985a). Those who develop language do not use it creatively or spontaneously. Their voices are often high-pitched, with unsual speech rhythm and intonation, which makes their speech sound sing-song or monotonous. They tend to use language in a very stereotyped, rote fashion, exhibiting excellent memorization skills but actually communicating very little, if any, meaning. They tend to repeat phrases and long commercial jingles. While it may seem that they are understanding what they are saying, they are usually parroting what they have heard. Despite good articulation and an adequate vocabulary, these children have a severe expressive language disorder.

Receptive language is affected as well. Children with autism may respond to brief phrases, but they find it very difficult to understand more complex commands. They learn better with visual than with auditory cues. At one point, language deficits were thought to be the primary cause of social withdrawal in children with autism, but these deficits are now regarded as secondary to the brain abnormality that causes the more fundamental disorder in relating to other people (Paul, 1987). Development of language is an important prognostic feature in autism. Children who develop language fare much better than those who do not (Schreibman, 1988).

Behavior Problems

The behavior problems in autism, particularly the restricted behavior repertoire and distressed response to environmental change, are among the most striking features

the disorder. Obsessive rituals and strict adherence to routines are common; including, for example, rigid insistence in eating at the same time every day and eating a restricted menu of foods, sitting in exactly the same position at the table, placing objects in a particular location, and touching every door knob one passes. Young children with autism may show intense attachment to unusual objects, such as a piece of plastic tubing, rather than a cuddly item like a teddy bear. They may not use toys in their intended manner, but focus instead on a part of a toy, such as the wheels on a toy truck, which they may spin incessantly. A common form of play is to line objects up in rows. Shining surfaces, rotating fans, and people's hair or beards may fascinate these young children. Older, more cognitively advanced individuals may become intensely preoccupied with train schedules, calendars, or particular patterns of numerical relationships. They will focus on these things to the exclusion of other activities.

Frequently, children with autism become upset and have intense tantrums if anything interferes with these rituals and preoccupations. Similar tantrums may be provoked by trivial departures from daily routines or changes in the environment. Stereotyped movements and self-stimulating behaviors, such as rocking, hand waving, arm flapping, toe walking, head banging, and other forms of self-injurious behavior are also common, especially among children with autism who have low IQs (Howlin & Rutter, 1987).

Other behavior problems associated with autism include sleep disturbances (especially in younger children), short attention spans, hyperactivity, tantrums, and aggressiveness. These behaviors, while not specific to autism, may be as difficult to manage as the characteristics of autism.

Intellectual Functioning

Children with autism function at various levels in the intellectual spectrum. However, about 70% have mental retardation: 35% have mild retardation, 15% have moderate retardation, and 20% have severe or profound retardation. Twenty-five percent fall in the borderline-to-normal range of intelligence (IQ 70–100) and about 5% have IQs over 100 (Minshew & Payton, 1988).

Psychological testing can be performed on children with autism, and the resultant IQs appear to be fairly accurate, providing the testing is done by a psychologist who is experienced in working with such children. The tests may need to be adapted, or nonverbal tests may be needed because the performance of children with autism is uneven. They tend to perform better on tests of visual-spatial skills and rote memory, and poorer on tasks requiring symbolic and logical reasoning. Some children with autism have restricted areas of higher functioning, called *islets of ability* or *splinter skills*. These include musical skills, such as perfect pitch, exceptional rote memory, an unusual capacity for jigsaw puzzles, or the ability to do rapid calculations of a specific kind, such as finding the day of the week for distant dates. Usually, these splinter skills relate to the individual's selected area of preoccupation and do not help them to solve problems in daily life. Even if the splinter skill involves some useful function, the child with autism is often not able to apply the skill to real life events.

Other Problems

Because children with autism are a heterogeneous group, there is no consistent pattern of physical or neurological abnormalities. A range of sensory disturbances has been reported, including both under- and oversensitivity to certain sounds, indifference to pain, and a preference for certain sensations, such as those that appeal to taste and smell rather than touch or sound. Most children with autism are clumsy and some have abnormalities of posture and movement (DeMyer, 1976). EEG abnormalities occur in approximately 80% of children with autism, but the incidence of seizures is not significantly different from the incidence in children with communication disorders (Minshew, 1991; Tuchman, Rapin, & Shinnar, 1991).

CAUSES OF AUTISM

There is, at present, nearly universal agreement that autism is caused by some form of brain damage or abnormality in brain development (Coleman & Gillberg, 1985; Lord, Mulloy, Wendelboe, et al., 1991; Nelson, 1991). The evidence for this includes: 1) the high incidence of EEG abnormalities; 2) the increased incidence of autism in certain diseases that are known to cause brain damage, such as untreated phenylketonuria (PKU) (see Chapter 10) and congenital infections; 3) the high frequency of mental retardation in autism (Wing, 1988); and 4) the high incidence of prenatal infections, prematurity, birth trauma, and so on (Bryson, Smith, & Eastwood, 1988; Mason-Brothers, Ritvo, Pingree, et al., 1990). These observations suggest that autism may result from brain damage sustained in a number of ways, including genetic abnormalities and environmental influences, and that the damage may be anatomical, physiological, and/or biochemical.

Neuroanatomical studies, based on imaging studies and examinations of the brains of persons with autism who have died, have identified abnormalities in the development of the cerebellum (Courchesne, 1991; Courchesne, Yeung-Courchesne, Press, et al., 1988; Ritvo, Freeman, Scheibel, et al., 1986) and the cerebral cortex (Piven, Berthier, Starkstein, et al., 1990). Findings such as these may provide information about when in the course of brain development the abnormalities developed.

Neurochemical studies have implicated various neurotransmitter disturbances in autism, although none consistently (Volkmar & Cohen, 1988). Some recent research has noted similar behaviors between children with autism and animals given opiates (Panksepp & Sahley, 1987), suggesting that abnormalities in these levels may play a role in autism (Weizman, Gil-Ad, Dick, et al., 1988; Young, Leven, Newcorn, et al., 1987).

A genetic basis for autism has been suggested by studies that have identified subgroups of children with autism who have a known genetic cause of brain injury, such as fragile X syndrome (Bregman, Leckman, & Ort, 1988; Reiss & Freund, 1990). Other studies have shown that autism occurs at higher rates among identical twins than among fraternal twins (Folstein & Piven, 1991; Smalley, Asarnow, & Spence, 1988) and that the risk of autism is much higher in families with one child

with autism than in the general population. Taken together, these studies indicate a genetic predisposition to autism.

DISTINGUISHING AUTISM FROM OTHER DEVELOPMENTAL DISABILITIES

Since intervention strategies vary according to diagnosis, it is important to distinguish autism from other developmental disabilities. The most common disorders that are mistaken for autism are mental retardation, childhood psychosis, sensory impairments, developmental language disorders, and progressive nervous system disorders.

Autism is distinguished from mental retardation by its characteristic social and behavior problems and by a somewhat different pattern of cognitive deficits. Children with autism shun social interactions and treat everyone, even parents, as objects; children with mental retardation generally enjoy social contacts. Children with mental retardation usually have equal delays in language, cognitive, and visual-perceptual skills, whereas children with autism have more prominent language impairments. However, most children with autism also have mental retardation, and many individuals with severe mental retardation display autistic features, such as stereotyped movements and self-injury (Capute, Derivan, Chauvel, et al., 1975).

Autism may also be confused with psychiatric disorders, such as schizophrenia (American Psychiatric Association, 1987). The key difference between the two syndromes is age of onset. Autism begins in the first 3 years of life, while schizophrenia rarely starts before adolescence. Furthermore, while the child with autism may behave in a bizarre manner, he or she will not have the delusions and hallucinations that are characteristic of schizophrenia. In addition, while a child with autism lacks imagination, a child with schizophrenia may live in a fantasy world. Finally, children with schizophrenia do not usually have mental retardation (see Chapter 23).

Children with sensory impairments may also demonstrate autistic features. Children with visual impairment often display self-stimulatory behaviors and lack the skills necessary for interpersonal interactions. They do not have the global language disorder that distinguishes children with autism, and their intelligence is usually normal. Furthermore, if there is improvement in their sensory function, the autistic features disappear. This makes it extremely important for the vision and hearing of children with autistic behaviors to be tested before the diagnosis of autism is confirmed.

Similarly, children with developmental language disorders may display shyness, echolalia, and some social withdrawal (see Chapter 19), but they typically do not show the deviant language features of autism, such as stereotyped utterances, abnormal social interactions, bizarre behaviors, and absence of a desire to communicate (Rutter, 1985a).

Finally, a group of progressive neurological diseases initially may be misdiagnosed as autism. Children with these disorders develop normally in infancy, then start to lose both intellectual and motor skills, and fall behind (Menkes, 1990). One example is Rett syndrome (Hagberg, Aicardi, Dias, et al., 1983; Percy, Zoghbi, Lewis, et al., 1987). Although children with autism may also seem to regress in their development, their loss of skills is usually restricted to language. Furthermore, most children with

autism have problems in social development that can be traced to the first year of life. The diagnosis of a progressive neurological disorder becomes evident as abilities continue to deteriorate over time.

Testing for Autism

There is no specific medical test for autism. Blood tests and EEGs may be abnormal, but are nonspecific. However, tests may be conducted to identify syndromes commonly associated with autism and to rule out other explanations for abnormal behavior. For example, a chromosome study would be performed if fragile X syndrome is suspected (see Chapter 16); metabolic studies might be ordered to test for PKU or other inborn errors of metabolism; and an MRI scan may be done to look for abnormalities in the cortex or cerebellum.

TREATMENT AND INTERVENTION APPROACHES

Michael Rutter, an eminent British child psychiatrist, has outlined five main goals of the treatment of autism: 1) the fostering of normal development, 2) the promotion of learning, 3) the reduction of rigidity and stereotypy, 4) the elimination of nonspecific maladaptive behaviors, and 5) the alleviation of family distress (Rutter, 1985b).

These goals are best met through a comprehensive educational and behavior management program that includes a highly structured education setting, language training, behavioral interventions, positive social experiences, and intensive parent involvement (Howlin & Rutter, 1987; Rogers & Lewis, 1989; Schreibman, 1988). Treatment should begin as early as possible, as there is some evidence that early intervention to promote acquisition of communication skills can lessen later maladaptive behaviors (Prizant & Wetherby, 1988).

Behavior therapy may be needed to modify behaviors that might otherwise interfere with development and learning. Reduction in stereotypical, rigid, ritualistic, and maladaptive behaviors (e.g., tantrums, aggression, self-injury) may be accomplished through a number of behavioral strategies. For example, behavior shaping can help to systematically positively reinforce approximations of desired communicative behavior and withdrawal of reinforcement can help to extinguish self-stimulatory behaviors. Other behavioral interventions attempt to increase social interaction (Schreibman, 1988). Parents are often used as co-therapists in these forms of intervention.

Fostering normal development must include language therapy with an emphasis on the pragmatics of language (i.e., using it to accomplish social goals) (Schuler & Prizant, 1987). Interactive and meaningful conversations should be modeled and practiced, and echolalia discouraged. With children with autism who are mute, attempts should be made to train verbal utterances, such as babbling or jargoning (Howlin & Rutter, 1987; Schuler & Prizant, 1987). Sign language can also be attempted, but it is often difficult for children with autism to learn. A novel approach, termed *facilitated communication*, is now being evaluated. The basic element of facilitated communication is providing physical support to the child's arm as he or she attempts to type messages on a keyboard or communication board (Biklen, 1990).

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This is done to overcome dyspraxia that may underlie the child's inability to use a communication device independently. Art and music therapy have also been used in attempts to communicate with children with autism nonverbally.

The education of children with autism usually requires highly structured programs with predictable routines and presentation of material in graded steps (Rogers & Lewis, 1989; Rutter, 1985a). Children with autism should be enrolled in preschool early intervention programs that stress communication skills and social interactions. By school age, many children with autism learn effectively in public school special education classes with children who function at similar developmental levels. Class sizes should be small, and activities should be broken into simple subunits to hold the children's interest and decrease stereotypical behavior. One-to-one interactions with teachers and fellow students are encouraged so that children with autism may develop social skills. Higher functioning children with autism may be integrated into regular education settings.

Medications play a limited role in the treatment of autism, as there is no pharmacological remedy for the disorder (Minshew & Payton, 1988). Certain medications, however, have been used to relieve some of the symptoms, including hyperactivity, irritable mood, social withdrawal, and aggression. The best studied of these medications is haloperidol (Haldol), a high-potency antipsychotic drug that has been shown to be effective in decreasing stereotypical behaviors, withdrawal, aggression, negativism, and irritability, as well as increasing performance on learning tasks (Anderson, Campbell, Grega, et al., 1984; Joshi, Capozzoli, & Coyle, 1988). Unfortunately, haloperidol is also associated with a high incidence of movement abnormalities (Perry, Campbell, Adams, et al., 1989). A medication that once looked promising in autism, fenfluramine, has more recently been shown to be largely ineffective. In addition, it interferes with discrimination learning and is poorly tolerated (Campbell, Adams, Small, et al., 1988; Stern, Walker, Sawyer, et al., 1990; Varley & Holm, 1990). Opiate antagonists, such as naltrexone, are being studied to see if they alleviate any of the hyperactive and maladaptive behaviors associated with autism. Preliminary reports show mild benefits (Campbell, Anderson, Small, et al., 1990).

Stimulants, used to treat hyperactivity, were formerly thought to aggravate stereotyped behaviors. But, methylphenidate (Ritalin) has been shown to be helpful in controlling hyperactivity in some children with autism (Birmaher, Quintana, & Greenhill, 1988; Strayhorn, Rapp, Donina, et al., 1988). Clonidine (Catapres), a newer medication for hyperactivity, which was developed to treat hypertension in adults, may also be useful for treating hyperactivity in children with autism. Lithium has also been used to treat the manic-like symptoms of autism (Steingard & Biederman, 1987).

Parents need emotional support and advocacy and, most of all, should be brought into the treatment process as teachers and co-therapists of their children. There is no doubt that having a child with autism is enormously stressful for the family. In addition to the normal stresses of having a child with disabilities, there are many additional demands as well as the frustration of caring for a child who provides few emotional rewards, requires intense supervision, has disturbed sleep, and ex-

hibits behavior that is difficult to manage. If emotional problems arise, family counseling is indicated.

KENNY: A CHILD WITH AUTISM

Kenny had problems from infancy. His early development was delayed, and his parents were quite concerned that Kenny would have mental retardation. They noticed that he did not "coo" or respond to sounds. He did not reach out to be picked up, and he seemed stiff and uncomfortable when they held him. Soon, his motor development improved. He sat by 8 months and walked by 15 months. His parents became hopeful that he did not have "brain damage." He also showed good visual-perceptual skills, being able to put together simple puzzles by 2 years of age and to build intricate block towers by 2½.

Yet, his parents remained concerned about his language, behavior, and relationships with other people. At 2 years of age, he neither spoke nor consistently followed 1-step commands. He was a loner. He showed no interest in playing with other children and barely acknowledged his parents. He still did not like to be held. Kenny exhibited no warmth and maintained no eye contact with others. He had many strange, ritualistic behaviors. He spun around, rocked, and constantly played with a string. He would fly into a rage when the furniture was moved or when he encountered new situations.

By 4 years of age, Kenny had developed some language, but it was very strange. He had an extraordinary memory for numbers and commercials. He would constantly carry a detergent bottle around the house singing its advertising jingle, and he would endlessly repeat strings of numbers. However, he still basically communicated with no one. He could not follow 2-step commands and spoke in only 1- or 2-word phrases. More often than not, he pointed to what he wanted.

At this time, psychological testing was performed. Kenny's IQ was 37, indicating he functioned around the level of an 18-month-old. However, he could build block towers and solve puzzles at a 4-year-old level. Because of his strange behavior, withdrawal, and reactions of rage, he was referred to a child psychiatrist. These symptoms, combined with good gross motor and visual-perceptual skills and severe mental retardation, led to a diagnosis of autism. His parents, in a sense, were relieved; they had a diagnosis, some place to start.

Even more important, Kenny was enrolled in an intervention program. He received the drug haloperidol to decrease his anxiety. His reactions of rage decreased. He entered a special school program where language and other reasoning skills were taught at an 18-month-old level. Behavior management techniques were used to help Kenny with new social situations and to reduce self-stimulatory behavior. At the same time, Kenny's parents received counseling from a social worker and followed through on a behavior management program set up by a behavioral psychologist.

By 6 years of age, Kenny had improved substantially. He could now form 3-word sentences, and the automatic repetition of words decreased. His behavior was better, and he could be brought into new situations without difficulty.

Kenny's eventual outcome is still unclear. He will continue to gain new skills, but his cognitive function will likely remain in the range of mental retardation. It is hoped that he will gain increased communication and social skills that will permit him to function in supported employment when he is an adult.

PROGNOSIS

Autistic features generally become less pronounced as the child grows, and stereotypic behavior decreases. By adolescence, the child's function will principally depend on his or her intelligence and speech skills Only about one-half of children with autism gain socially useful speech, usually by 5 years of age (Rutter, 1985a). The child with autism and moderate-to-severe mental retardation will function in a manner similar to other children with mental retardation, although he or she will have poorer language skills, possibly better problem-solving abilities, and a decreased interest in social interactions. Even among higher functioning individuals with autism, abnormalities of verbal expression, concrete thought processes, social awkwardness, and stereotyped and inappropriate social behaviors tend to persist (Wing, 1988). Overall, about 15% of children with autism have a good outcome, 15% a fair outcome, and 70% a poor outcome in terms of functioning independently in society as an adult. The majority live at home or in supervised living situations (Rumsey, Rapoport, & Sceery, 1985). Most individuals with autism are independent in self-care skills and can participate in activities of daily living (Wing, 1985). Some young adults can engage in supported employment, especially in jobs that require the use of their visual-motor skills. Those with normal intelligence can often live and work independently.

SUMMARY

Autism appears to be a distinct syndrome. Its principal characteristics are a global language disorder, abnormal behavior patterns, social isolation, and, usually, mental retardation. Its causes are many. Differentiation from other disabilities, such as mental retardation, psychiatric illness, sensory impairments, and progressive neurological disorders, is essential for proper therapy to be possible. Therapy consists of an interdisciplinary approach that includes psychiatry, speech-language pathology, behavioral psychology, and social work. At this point, the value of medication is uncertain. In adolescents and adults, the bizarre behavior is less apparent, but prognosis is generally poor. The children with the best hope for the future are those with the higher IQ scores.

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INSTITUTE • *for the* • STUDY • *of* DEVELOPMENTAL DISABILITIES

The University Affiliated Program of Indiana

FACTS ABOUT AUTISM

Indiana Resource Center for Autism

Indiana University

This document was developed and disseminated by the Indiana Resource Center for Autism (IRCA) located at the Institute for the Study of Developmental Disabilities (ISDD) at Indiana University, Bloomington. The ISDD is *the University Affiliated Program of Indiana*.

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FACTS ABOUT AUTISM

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c. 1991

WHAT IS AUTISM?

Autism is a diagnostic label for a lifelong developmental disability caused by a brain dysfunction.

- It occurs in approximately 1 in 1000 people of all races, cultures, and educational backgrounds.
- The disorder shows itself in infancy or early childhood.
- It is accompanied by mental retardation about 80% of the time.
- It can also occur with other conditions such as deafness, Down syndrome, Fragile X syndrome, and epilepsy.
- About four out of five people with autism are male.

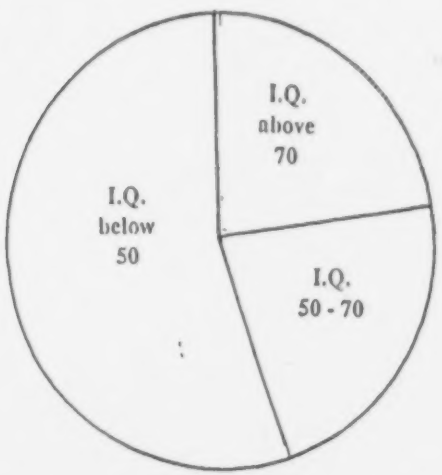
People with autism vary widely in abilities, intelligence levels, and behavioral characteristics. Across the spectrum of those diagnosed with autism, the common components are:

- Significant impairments in language and communication abilities,
- Significant impairments in social skills, and
- A limited number of activities and interests.

WHAT CAUSES AUTISM?

There is no single known cause for autism. Experts do not know exactly what is different about the structure, function, or chemistry of the brain in an individual with autism.

- Research is showing that the brain cells of people with autism work together in an unusual manner.
- The chemicals which carry messages between brain cells may also be too high or too low.
- Apparently, people with autism do not perceive or process incoming sensory information (hearing, sight, touch, smell, and movement) in the same way as other people.



Mental Retardation in People with Autism

People who have autism may also have other disorders such as. . .

mental retardation,
seizures,
genetic diseases,
cerebral palsy, or
brain malformations.

Autism, however, is a separate disorder aside from any other problems.

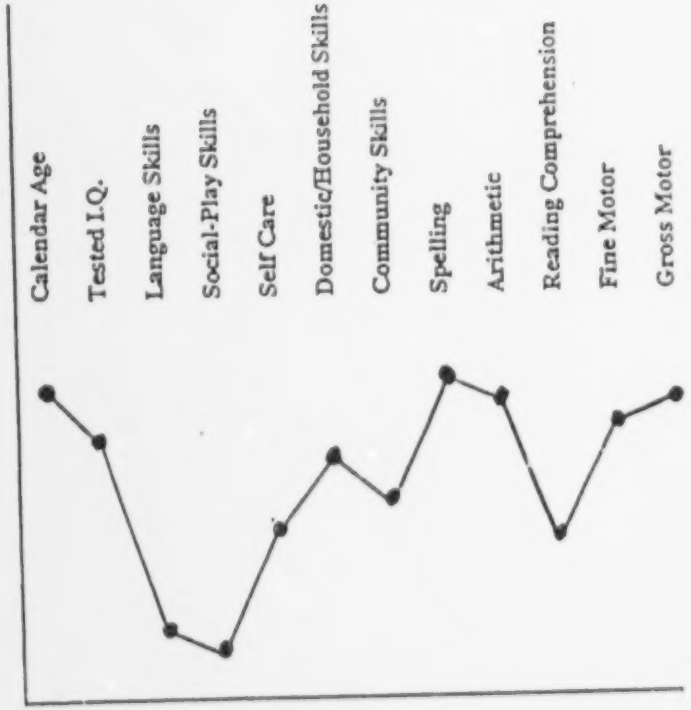
- There is no definite medical test which can diagnose autism.
- Genetic factors are considered to be one possible contributing cause of autism.
- In some families there seems to be a pattern of autism and/or associated problems of learning or language.
- Other causal factors being researched include viral infections during pregnancy, metabolic disorders, and birth complications.

HOW IS AUTISM DIAGNOSED?

The diagnosis of autism is best made on information compiled by various members of an interdisciplinary assessment team. Teams usually consist of a psychologist, a teacher, a speech/language pathologist, and a social worker. Other professionals such as a physical or occupational therapist, doctor, or nurse may be important additions to the team.

It is important that the team gather developmental and behavioral information from the family and school/program. A markedly uneven developmental pattern alerts the team to the possibility of autism. An early history of language delay and problems in the development of toy play, play with peers, pretend play, and odd use of eye contact in interactions with adults are other possible indicators.

Another characteristic often seen in autism is abnormal reactions to sensory stimuli. For example, people with autism may mouth or smell items in preference to looking at them or may become very upset when they hear a particular noise or see a particular object.



Sample Developmental Profile of a Person who is More Able and has Autism

In most individuals with autism these problems are most apparent between ages 3-6, but continue through the school years and into adulthood.

Individuals with autism who are more able (those with IQs over 70) may seem to have hyperactivity or a learning disability. But they also have significant social and communication problems which continue throughout their lives.

WHAT CAN HELP A CHILD WITH AUTISM?

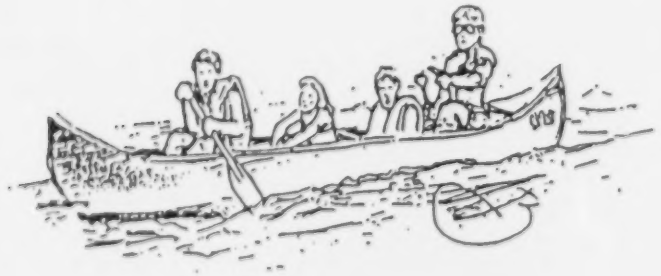
Children with autism need to be identified early. Families and teachers can then communicate and teach more effectively in ways that the child can understand, before the child, family, and school staff become very frustrated.

Children with autism need an individualized learning program. The emphasis needs to be on helping the child learn ways to communicate and on arranging the environment so that it is more consistent and predictable.

Children with autism need chances for successful experiences including reinforcement for small steps forward.

They need learning activities which incorporate their strengths and interests. The learning activities need to be functional and have a clear purpose that can eventually be understood by the child with autism.

They need planned integration with peers who are following the typical developmental pattern.



Most children with autism learn best through visual means. Teaching with objects and pictures, and providing peers to imitate helps them learn.

They also learn best through participation in real situations, since skills taught in isolation may not be remembered when the person with autism tries to use them in the real world.

Some children can benefit from medication if it is given for a specific problem such as anxiety, hyperactivity, depression, or other interfering behaviors. Family and doctor can work together to assess the child's need for medication. However, there is no medication that cures autism.

WHAT CAN HELP THE FAMILY OF A PERSON WITH AUTISM?

The family will need a comprehensive, coordinated, and flexible system of family supports throughout the lifetime of the person with autism.

The family needs information and knowledge about autism. Help and understanding of extended family members and friends will be an important support to the family.

An accepting and educated community as well as parent and sibling support groups may be helpful to families.

The family might need help in structuring daily living and teaching self care skills, such as bathing, dressing, eating, toileting, and sleeping. They might need help in planning and carrying through successful community and family outings.

The family often feels more successful if they can learn some specific behavioral strategies for their child with autism because it quickly becomes apparent that traditional disciplinary techniques are not successful with these children.

Families may need a coordinator/ advocate to help them access the best services in schools and other community facilities. This person might be a case manager from a state agency, a social worker at the agency where the person is enrolled in a program, an advocate from another service program, or a friend.

Unfortunately, there are presently few identifiable resources to help families obtain the needed information and support at home. Too much depends on the resourcefulness of each family.

Professional supports may include, but are not limited to:

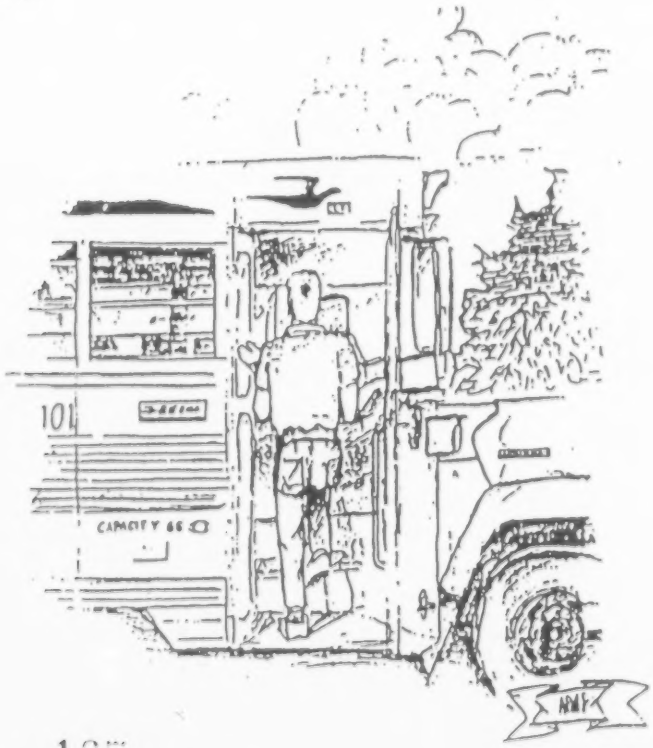
- Respite in or out of the home. This help should be provided by a trained and knowledgeable person who can baby-sit or can help implement a program to teach the individual a specific skill or activity.
- Crisis intervention.
- Behavioral, speech, recreational, occupational, or other therapies.

WHAT HAPPENS TO A CHILD WITH AUTISM IN THE PUBLIC SCHOOLS?

Once the diagnosis of autism has been made, autism should be listed on the Individualized Education Plan (IEP).

From the child's first years in school, long term planning to promote independent functioning should be considered when choosing IEP goals.

A knowledgeable and caring advocate for the student will contribute towards a successful experience in the school system.



Placement or assignment to a specific program or combination of programs must be made on the basis of the individual student's strengths and needs.

Class placement could range from regular education full or part time with supports to programs for students with other types of handicapping conditions, mild or severe.

A combination of placements may be used if this best meets the student's needs, again depending on the student's Individual Educational Plan.

For most students with autism, speech/ language therapy will be required.

Often the curriculum will be centered on functional skills, skills that will enable the student to live as competently as possible as an adult. These functional skills may be part of a community-based program to learn job, social, and leisure skills. Students can practice social and language skills as well as learn by doing while participating in actual community settings.

A Vocational Rehabilitation Counselor must become involved in the student's educational planning in the last four years of school.

Special education districts may elect to permit students to continue their education until they are 21 years old.

WHAT HAPPENS TO AN ADULT WITH AUTISM?

Children with autism grow up to become adults with autism. However, research indicates that early identification and individually designed educational programs can help prepare and assist the person with autism to lead a meaningful and productive life.

Adults with autism will continue to learn. Their strengths, interests, and skills may change with schooling, other programs, or interventions. However, they will continue to have deficits in communication and social skills and to exhibit a restricted number of interests.

Planning for the adult years must begin early. During the school years, projections for living arrangements, job training, and leisure skills must be made by the family with input from professionals working with the child. Schooling should then be tailored towards building a foundation for all aspects of the person's adult life.

Adults with autism may live at home, with roommates in group homes or apartments that are supervised, or alone in homes or apartments with minimal supports. A few live completely independently. A very few marry and live with spouses.

A small percentage, who do not have mental retardation, attend college with support.

A high percentage of people with autism are receiving training ranging from daily living skills and sheltered work to training and placement in supported work through developmental disability agencies.

Adults with autism continue to have a restricted repertoire of recreational interests. They need help to attend concerts, sports events, or church, and to use libraries, swimming pools, and other community facilities of their choice.

They continue to benefit from individualized exercise activities, such as swimming, bowling, and bike riding, that they can share with others in the community. They usually like to continue their involvement in the community through shopping, eating out, and other daily living activities, often with family, friends, and co-workers.

A few adults with autism drive. Other adults can learn to use public transportation; some depend on family or caregivers for mobility in the community.

WHAT JOBS CAN PEOPLE WITH AUTISM DO?

Some adults work at regular jobs in their community, often with some support from job coaches or supervisors. Other work in sheltered workshops.

People with autism, regardless of their functioning level, need certain supports built into employment and job training.

- They need a job which emphasizes their strengths and likes.
- They often need the job tasks organized and structured for them to minimize decision making.
- Written or pictured schedules and check lists can help organize job tasks and split a large job into several simpler steps.

Some examples of jobs people with autism are doing include library work, computer data entry, computer programming, janitorial/cleaning work, kitchen work such as dishwashing and basic meal preparation, assembly and packaging, office work, newspaper delivery, and yard care.

People with autism need jobs which are predictable but not necessarily repetitive. Skills for communication, social interaction, and independence are essential for success in the workplace.

Most people with autism will need specific job training and an understanding supervisor who can help problem solve and run interference when issues or problems of a communicative, social, or sensory nature arise at the work place.

SELF-INJURY

Answers to Questions for Parents, Teachers, & Caregivers

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The University of Minnesota's Institute for Disabilities Studies, directed by Travis Thompson, Ph.D., was established in 1987 to conduct basic and applied scientific research on preventing and intervening in developmental disabilities, and to design treatment and educational methods for people with disabilities. The Institute's research focuses on the prevention of disabilities arising from poverty; on behavioral and emotional problems associated with disabilities; and on disabilities that occur later in life. Because no single field of study can solve the complex problems of developmental disabilities, the Institute for Disabilities Studies is dedicated to interdisciplinary collaboration, making it a unique program within the University of Minnesota and across the country.

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Institute for Disabilities Studies,
University of Minnesota

Written by Bruce L. Bakke, Ph.D.,
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Designed by Anna Fellegy;
cover by Geri Thompson.

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The Minneapolis Foundation.

The following contents do not necessarily represent the positions and policies of each organization mentioned in this brochure.

One in five people with mental retardation injures her or himself, causing pain and suffering to themselves, their families and others around them. This guide for parents, teachers and other caregivers of people who have developmental disabilities describes the more common types of self-injury and discusses methods for identifying causes. Interventions are discussed and information is provided concerning sources for further assistance.

CHARACTERISTICS OF SELF-INJURY

What is self-injurious behavior and how common is it?

Self-injurious behavior (SIB) is repetitive behavior that causes physical harm. Usually the behavior takes a very similar form every time it occurs -- for example, one child may bruise the side of her head by hitting herself with the knuckles of one hand. Another may repeatedly bite one place on his right wrist. SIB is different from suicidal behavior and suicidal gestures, and is seen almost exclusively in people with mental retardation and other developmental disabilities. In most instances, self-injury can be successfully treated, especially by intervening early in the development of the problem. While self-injury is rarely life-threatening, without treatment it can sometimes worsen to the point of causing permanent damage. A few people with severe self-injury blind themselves or suffer hearing loss, destroy parts of their bodies (e.g., portions of fingers or lips), produce concussions, or cause repeated damage which leads to lingering infections.

Do all children who bump their heads or hit themselves develop the problem of self-injury?

No. About 17% of infants without a disability periodically hit their heads against their cribs or occasionally hit their head or face with their hand when they are tired or frustrated. Nearly all non-disabled infants stop hurting themselves by the time they are two years old. But as many as one in five children with mental retardation continue hurting themselves periodically for months and years, sometimes severely.

My four year old son slaps his face repeatedly, but he doesn't leave any bruises, just reddened skin. Is this a problem?

Face slapping or any other behavior that is performed often enough or intensely enough to cause reddening or breaking of the skin, bruises, bleeding, or other signs of tissue damage should be discussed with a professional experienced with self-injurious behavior in people with developmental disabilities. Sources of help include special education teachers, pediatricians, behavior analysts, social workers, child psychiatrists and psychologists, and pediatric neurologists.

Do children with some particular disabilities have more problems with self-injury than children with other disabilities?

Children with several uncommon disabling conditions, such as Autism, Cornelia de Lange syndrome, Fragile X syndrome, Lesch-Nyhan syndrome, and Rett syndrome have problems with self-injury more often than children with other developmental disabilities. However, since as many as 20% of children with disabilities display self-injury at some time in their lives, the problem extends well beyond these rarer disabilities. People wishing further information about specific disabilities often associated with self-injury should contact the resources listed at the end of this brochure.

CAUSES OF SELF-INJURY

What is known about the causes of the problem?

Thirty years ago, some writers speculated that children who hurt themselves were born the same as other children but that their self-injury resulted from a cold or detached style of mothering. There is no evidence to support this theory.

Today, most experts realize that self-injury usually has more than one cause. There may often be an underlying biological tendency for a child to self-injure. How often, under what circumstances and how intensely the child self-injures often depends on learning experiences, which can cause the self-injury to decrease or sometimes grow much worse.

Can medical problems cause self-injurious behavior?

Several medical conditions can lead to self-injury. Children with ear infections, for example, may try to reduce their discomfort by hitting or slapping at their ears. Similarly, they may repeatedly scratch at an area of itching skin, and continue to scratch when the skin begins to heal. Once the earache or skin irritation clears up, the self-injury usually stops. If the self-injury continues after the medical problem is over, another cause for the behavior should be considered.

Can dietary factors such as sugar, artificial coloring, or other food additives cause self-injury?

There is little carefully done research on the effects of diet or food ingredients on self-injury, or on megavitamin therapy as a treatment for self-injury. The studies on food and hyperactivity (extreme restlessness and overactivity) in children show no consistent effect of diet on behavior. For most children, activity level does not appear to be changed by the items in a normal diet, but a small number of children may be affected by diet.

I often see my child hurting himself when he is angry. For example, he bumps his head when it is time to put on his shoes. Why does he do this?

Children sometimes learn to avoid or delay doing things that they don't like by hurting themselves. Perhaps the youngster finds it difficult to put on his shoes, or does not enjoy the activity that will follow once he is dressed. Maybe he just prefers to continue with whatever he is doing. Because it is

difficult for adults to continue to request something from a child who is engaged in self-injury, some children learn to control what happens in their lives by hurting themselves. Self-injury is especially likely to be learned if the child cannot speak and has no other effective way to communicate.

My child speaks only a few words. Is it possible that she is trying to tell us something by hurting herself?

Self-injury can be an effective method for getting attention from adults, because the parent's natural response is to immediately go to the child to see what is wrong and to try to stop the self-injury. Sometimes it is necessary for adults to physically prevent the child from injuring him or herself. Children who have difficulty communicating can learn that attention can be gotten at any time by hurting themselves. Beyond simply gaining attention, children can also learn to hurt themselves to obtain other things they need or want. These may include preferred foods, favored activities, or being left alone. Self-injury is disturbing and even alarming to adults, and they will do whatever they can to stop it. Adults often offer various things to the child until s/he stops self-injuring. Unfortunately, the child may self-injure for a different reason the next time, and the process of adult guessing will be repeated again and again, unless a more satisfactory form of communication is developed.

Even though our child communicates very well, he threatens to scratch his face or hurts himself in other ways when he wants something he shouldn't have. Since he tells us exactly what he wants, communication can't be the reason for his self-injury.

Self-injury can still be a powerful and quick way for a child to get what he wants, at least part of the time. Seeing children deliberately hurt themselves is extremely upsetting for parents and others. It is very difficult not to give in at least occasionally, and provide what the child wants to stop the self-injury. Although it is not intended, this rewards the child's self-injury and can cause the self-injury to continue.

So far, none of this seems to fit my child. She has Down syndrome, and had a complete medical evaluation showing no medical problems that could account for her self-injury. It doesn't seem to be an attempt to communicate or to get attention. In fact, she likes to be alone. She rocks for long periods of time. When she rocks, she bumps against the wall and has caused a bruised spot that seems never to heal.

Some children perform a repetitive movement that results in skin, muscle, or even bone damage because it is repeated over and over again. The stimulation produced by the repeated movement may be pleasant to her, much as rocking is enjoyed by a baby. The injury is a by-product of the way the movement is performed (in this case, by constantly bumping against the wall). Similar problems are seen in children who have impaired vision. A child with a visual handicap might learn to press a finger into the eye because of the flashes of light this mechanical stimulation produces through the optic nerve. Obviously, this can cause physical damage to the eye.

I can see that repeating the same movement can cause injury as an accidental by-product of the movement. However, when my son bangs his head, it seems that his only purpose is to damage himself.

A different kind of self-stimulation can result from self-injury: Sufficient pain causes the release of "endogenous opioids," which are natural chemicals in our bodies that protect us from feeling intense pain. Endogenous opioids can also produce feelings of euphoria, such as the so-called "runner's high" that some people experience when running marathons. Some people may self-injure in order to be stimulated by these pleasant effects of endogenous opioids. Research on endogenous opioids as a cause of self-injurious behavior is just beginning, and may lead to new treatments for some self-injury.

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TREATMENTS FOR SELF-INJURY

With so many different causes, how is self-injury treated?

The first step is to try to discover the causes of the child's self-injurious behavior. It is important to identify any medical problems that might be responsible. This requires a thorough examination by a physician familiar with children with mental retardation. Other causes for self-injury can be identified by examining the circumstances in which the child self-injures. When the behavior occurs primarily in adult company but rarely when the child is alone, it is often directed at getting attention or other things that the child needs or wants. Self-injury that occurs when the child is asked to do something or during activities the child dislikes may be attempts to avoid unpleasant activities. The child who is just as likely to self-injure when alone as when he or she is with adults may be showing behavior that is a form of self-stimulation. Each of these causes suggests a different avenue of treatment to a professional experienced in treating self-injury.

Once causes are identified, what treatments are available?

A range of treatments are available, including providing more rewarding activities at which the youngster can easily succeed, providing communication training, decreasing the demands made on a child, and drug treatment. A positive environment with appropriate training, social, recreational, and other experiences must provide the foundation for any treatment for self-injury. That environment must provide activities with the correct amount of challenge: Tasks should be easy enough for the child to be successful. Assessing the environment of a self-injurious child, and selection and use of effective treatments, usually require the assistance of a developmental disabilities professional. Treatments should be matched to the cause identified. For example, children who learn to hurt themselves to gain attention from parents, teachers or other people caring for them can usually be

taught to seek that attention in healthier ways, making it unnecessary for them to hurt themselves. Teaching children to develop other communication methods, or to use other constructive ways of gaining adult attention is often enough to reduce self-injury. In other circumstances, self-injury is thought to be caused mainly by a biological condition, such as a brain chemical imbalance. In such instances, it may be necessary to treat the underlying problems with a drug intended to correct the imbalance.

My child takes medication for self-injury. She still hurts herself, but not as often.

Medications are currently one of the most common forms of treatment for self-injury. The medications usually tried for self-injury are called neuroleptics, which are the same types of drugs used for treating some major mental illnesses. These and other drugs can be helpful for certain conditions, however they are rarely used alone except when the person clearly has mental illness as well as mental retardation. A disadvantage of some drug treatments is that they can have both immediate and long-term unwanted side effects, some of which can be very serious. Treatment with medication always requires consultation with a physician.

Some friends have suggested that I spank my daughter for self-injury. Is this a good idea?

No. Positive, non-aversive interventions are usually sufficient to reduce or eliminate self-injurious behavior, and parents are urged not to use spanking, slapping, or scolding to control self-injury. Punishment procedures by themselves are not an appropriate treatment. However, as one part of a carefully designed overall treatment program in closely supervised clinical settings, various response suppression procedures have been reported to be effective under some circumstances. Such procedures are controversial. Parents wishing further information on this topic are encouraged to contact the following resources:

1) The position statement on the use of aversive and deprivation procedures of the Association for Retarded Citizens Minnesota (ARC MN). This statement is available by calling ARC MN at (800) 582-5256 or (612) 827-5641, or from the Institute for Disabilities Studies, (612) 627-4537. Addresses for both organizations are listed among the resources at the end of this brochure.

2) The 1989 National Institutes of Health Consensus Development Conference Statement, *Treatment of Destructive Behaviors in Persons with Developmental Disabilities*. Single copies can be obtained from the Director of Communications, Office of Medical Applications of Research, National Institutes of Health, Building 1, Room 260, Bethesda, MD 20892.

When my child is busy, there seems to be less self-injury.

Whether at home or at school, keeping a child occupied with enjoyable activities at which they can easily succeed, and providing frequent adult attention will often reduce self-injury. The key to reducing self-injury by providing these activities is to promote the child's active responding and learning of new skills. It appears that it is most helpful to have the child participate in doing things, rather than doing things to or for the child.

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XV. Physical Disabilities

- Misconceptions about Persons with Physical Disabilities
- Wheelchair Etiquette
- Cerebral Palsy
- Epilepsy: A Fact Sheet (NICHCY Sheet)
- First Aid for Epileptic Seizures
- I Am Not Defined by My Disorder
- Understanding Spina Bifida
- Taking Big Steps
- Acquired Pediatric Brain Damage: Diverse Causes
- The Story of My Head Injury
- Musculoskeletal Conditions
- Juvenile Rheumatoid Arthritis
- Muscular Dystrophy
- Additional Physical Conditions
- Cancer

Misconceptions about Persons with Physical Disabilities

MYTH > Cerebral palsy is a contagious disease.

FACT > Cerebral palsy is not a disease. It is a nonprogressive neurological injury. It is a disorder of muscle control and coordination caused by injury to the brain before or during birth or in early childhood.

MYTH > Physical disabilities of all kinds are decreasing because of medical advances.

FACT > Because of advances in medical technology, the number of children with severe disabilities is increasing. The number of survivors of serious medical conditions who develop normally or have mild impairments, such as hyperactivity and learning disabilities, is also increasing.

MYTH > The greatest educational problem involving children with physical disabilities is highly specialized instruction.

FACT > The greatest educational problem is teaching people without disabilities about what it is like to have a disability and how disabilities can be accommodated.

MYTH > The more severe a person's physical disability, the lower his or her intelligence.

FACT > A person may be severely physically disabled by cerebral palsy or another condition but have a brilliant mind.

MYTH > People with epilepsy are mentally ill.

FACT > People with epilepsy (seizure disorder) are not any more or less disposed to mental illness than those who do not have epilepsy.

MYTH > Arthritis is found only in adults, particularly those who are elderly.

FACT > Arthritic conditions are found in people of any age, including young children.

MYTH > People with physical disabilities have no need for sexual expression.

FACT > People with physical disabilities have sexual urges and need outlets for sexual expression.

MYTH > The effects of traumatic brain injury are not distinguishable from those of other disabilities, such as mental retardation, learning disabilities, and emotional or behavioral disorders.

FACT > A person who has had traumatic injury to the brain may, indeed, show cognitive, social, emotional, and behavioral characteristics much like those associated with other disabilities. However, the causes of these characteristics, their prognosis and course, and their management may be quite different from those of other disabilities.

Hallahan, D. P. & Kauffman, J.M. (1997). Exceptional Learners: Introduction to Special Education. (7th Ed.). Allyn & Bacon: Boston, MA. p. 397.

WHEELCHAIR ETIQUETTE

Have you ever felt uncomfortable around a person in a wheelchair? If it was because you didn't know what to do or how to help, here are a few points to consider. . .

THINGS TO KNOW:

- There is a wide range of physical ability among those who use wheelchairs, and people who use them may require different degrees of assistance.
- Some people do not use wheelchairs exclusively. They may also use canes, leg braces or, in some cases, no assistive devices at all.

THINGS TO DO: COMMUNICATING

- Relax and make eye contact. Acknowledge the person's presence.
- Sit down when possible to give the person a more comfortable viewing angle.

THINGS TO DO: ASSISTING

- When offering assistance to a person in a wheelchair, wait until your offer has been accepted *before* you help. Listen to any instructions the person may want to give.
- *Ask* how you may help. Simply moving a piece of furniture may be all that is needed.
- Make sure the person is ready *before* you start pushing the wheelchair.
- It is a common experience for people who use wheelchairs to be told that some place is accessible when it is not. Consider distance, weather, and physical obstacles such as stairs, curbs or hills when *you* give directions.

CEREBRAL PALSY

Cerebral palsy is the term used to describe a collection of disorders which prevent the child from controlling their muscles normally. The most common form, spastic cerebral palsy, causes the muscles to be abnormally and continuously contracted, or tight. One quarter of all children with cerebral palsy have spastic cerebral palsy involving all four limbs (quadriplegia), but it can affect just the arms, just the legs (diplegia), or one side of the body more than the other (hemiplegia). The other main type, dyskinetic cerebral palsy, causes slow writhing movements, often more in the arms and face than the legs. Both types can occur in the same child.

There are many causes of cerebral palsy. It used to be blamed on lack of oxygen during a difficult delivery, but this causes less that 10% of cases. Usually it is due to an abnormality of brain development or damage to the developing brain from one of a wide variety of causes during pregnancy. Prematurity is a major factor: birth weight under 3 pounds increases the risk twenty fold. In about one quarter of cases, no cause can be found. although the damage is usually present at birth, five to 10% of cases are caused by damage in early childhood from a brain infection or trauma. Because cerebral palsy is caused by a brain injury in the past, and because brain tissue does not heal, the disability does not get progressively worse or better. Because the cerebral palsy is just one manifestation of brain injury, it is not surprising that these children typically have other disabilities. Intelligence, hearing, vision and speech can be affected. One third of children with cerebral palsy have normal intelligence, but still are likely to have learning disabilities. About one third develop a seizure disorder, usually by the age of two.

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free, Voice/TT)
*SpecialNet User Name: NICHCY ** Internet: nichcy@capcon.net*

General Information About

EPILEPSY

Definition

According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

Some people can experience a seizure and not have epilepsy. For example, many young children have convulsions from fevers. These febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure does not mean that the person has epilepsy.

Incidence

About two million Americans have epilepsy; of the 125,000 new cases that develop each year, up to 50% are in children and adolescents.

Characteristics

Although the symptoms listed below are not necessarily indicators of epilepsy, it is wise to consult a doctor if you or a member of your family experiences one or more of them:

- "Blackouts" or periods of confused memory;
- Episodes of staring or unexplained periods of unresponsiveness;
- Involuntary movement of arms and legs;
- "Fainting spells" with incontinence or followed by excessive fatigue; or
- Odd sounds, distorted perceptions, episodic feelings of fear that cannot be explained.

Seizures can be generalized, meaning that all brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are partial when those brain cells not working properly are limited to one part of the brain. Such partial seizures may cause periods of "automatic behavior" and altered consciousness. This is typified by purposeful-looking behavior, such as buttoning or unbuttoning a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not recalled.

Educational Implications

Students with epilepsy or seizure disorders are eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (Public Law 94-142). Epilepsy is classified as "other health impaired" and an Individualized Education Program (IEP) would be developed to specify appropriate services. Some students may have additional conditions such as learning disabilities along with the seizure disorders.

Seizures may interfere with the child's ability to learn. If the student has the type of seizure characterized by a brief period of fixed staring, he or she may be missing parts of what the teacher is saying. It is important that the teacher observe and document these episodes and report them promptly to parents and to school nurses.

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Depending on the type of seizure or how often they occur, some children may need additional assistance to help them keep up with classmates. Assistance can include adaptations in classroom instruction, first aid instruction on seizure management to the student's teachers, and counseling, all of which should be written in the IEP.

It is important that the teachers and school staff be informed about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. Most parents find that a friendly conversation with the teacher(s) at the beginning of the school year is the best way to handle the situation. Even if a child has seizures that are largely controlled by medication, it is still best to notify the school staff about the condition.

School personnel and the family should work together to monitor the effectiveness of medication as well as any side effects. If a child's physical or intellectual skills seem to change, it is important to tell the doctor. There may also be associated hearing or perception problems caused by the brain changes. Written observations of both the family and school staff will be helpful in discussions with the child's doctor.

Children and youth with epilepsy must also deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, uncertain occurrence, loss of self control during the seizure episode, and compliance with medications. To help children feel more confident about themselves and accept their epilepsy, the school can assist by providing epilepsy education programs for staff and students, including information on seizure recognition and first aid.

Students can benefit the most when both the family and school are working together. There are many materials available for families and teachers so that they can understand how to work most effectively as a team.

Resources

Epilepsy Foundation of America. (1987). *Epilepsy: You and Your Child, Information for Parents.* Landover, MD: Epilepsy Foundation of America.

Freeman, J.M., Vining, E., Pillas, D. J. (1993). *Seizures and Epilepsy in Childhood: A Guide for Parents* (rev. ed.). Baltimore, MD: Johns Hopkins University Press. (Telephone: 1-800-537-5487.)

Kobrin, Eileen R. (1991). *Issues and Answers: A Guide for Parents of Teens and Young Adults with Epilepsy.* Landover, MD: Epilepsy Foundation of America. (Telephone: 301-577-0100.)

Reisner, H. (Ed.). (1988). *Children with Epilepsy: A Parent's Guide.* Kensington, MD: Woodbine House. [Telephone: 301-468-8800 (in DC area); 800-843-7323 (outside DC area).]

Organizations

Epilepsy Foundation of America (EFA)
4351 Garden City Drive, Suite 406
Landover, MD 20785
(301) 459-3700; (800) EFA-1000 (Toll Free)
(301) 577-0100, for Publications

National Institute of Neurological Disorders and Stroke (NINDS)
National Institutes of Health
Building 31, Room 8A06
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5751

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UPDATE 12/93

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FIRST AID FOR EPILEPTIC SEIZURES

A major epileptic seizure is often dramatic and frightening. It lasts only a few minutes, however, and does not require expert care. These simple procedures should be followed:

- REMAIN CALM. You cannot stop a seizure once it has started. Let the seizure run its course. Do not try to revive the child.
- If the child is upright, ease him to the floor and loosen his clothing.
- Try to prevent the child from striking his head or body against any hard, sharp, or hot objects, but do not otherwise interfere with his movement.
- Turn the child's face to the side so that saliva can flow out of his mouth.
- DO NOT INSERT ANYTHING BETWEEN THE CHILD'S TEETH.
- Do not be alarmed if the child seems to stop breathing momentarily.
- After the movements stop and the child is relaxed, allow him to sleep or rest if he wishes.
- It isn't generally necessary to call a doctor unless the attack is followed almost immediately by another seizure or the seizure lasts more than ten minutes.
- Notify the child's parents or guardians that a seizure has occurred.
- After a seizure, many people can carry on as before. If, after resting, the child seems groggy, confused, or weak, it may be a good idea to accompany him or her home.

SOURCE: Courtesy of Epilepsy Foundation of America.

Hallahan, D. P. & Kauffman, J. M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 396.

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I Am Not Defined by My Disorder

This is a shared story by a father and his daughter. Both tell their own side. Jennifer's remarks are in boldface.

I had just sat down to dinner with my wife, Susan, our daughter, Jennifer, nearly 13, and son, Jonathan, 8, when Jennifer said her tongue mysteriously felt as though she'd bitten it. They mystery's frightening answer unfolded a few mornings later: Jennifer's arms flew up and her body jerked and she crashed to the floor, shaken into unconsciousness in the hands of an invisible, raging giant.

I felt helpless, unable to do more than cradle my daughter's head on my knees. Hours later in a hospital emergency room, I began to learn more about the strange giant that had taken hold of Jennifer- the chronic brain disorders that are collectively termed epilepsy.

"Is that what I have?" Jennifer asked hazily after a nurse mentioned the word. "Epilepsy?" I looked down at her on the hospital bed. She was half-conscious with the pounding, sledge-hammer headache that, we would learn, sometimes follows a grand mal seizure. "I think so," I said, squeezing her hand. But I didn't know anything about epilepsy, and so I looked away to hide my fear.

I don't mind my epilepsy. If I had to pick a disorder to live with, this would probably be it. The whole thing is kind of fascinating: why some people are epileptic, how seizures are triggered, which drugs work for which seizures.

I now know that epilepsy is an ancient and mysterious malady, still misunderstood, that afflicts about one percent of the U.S. population- some 2 million people, estimates the Epilepsy Foundation of America. It's important to know that most of them lead normal lives. They attend schools, hold jobs, raise families. They make history: Alexander the Great had epilepsy. So did Socrates, Napoleon, van Gogh, and Alfred Nobel.

Epilepsy's causes are unclear. Its manifestations- seizures- result from the excessive, disorderly and unfiltered firing of neurons within the brain. Grand mal seizures are the ones in which the body thrashes and consciousness departs. Although frightful, they cause no lasting injury. If you see someone in the grip of a grand mal seizure, do no more than cushion his head for the few minutes the seizure will last. Don't try to restrain him or force anything into his mouth. Other forms of seizures include absence spells (brief losses of awareness, occasionally with rapid eye blinking) and partial seizures (jerking seizures on one side of the body, or in one leg or arm). Many children with epilepsy outgrow their seizures.

We were never sure if it was the side effects of her first anticonvulsant drugs or the still-recurring seizures, but entire days began disappearing from Jennifer's memory. Her grades plummeted. After she tumbled down a flight of stairs at school, educators held a meeting to consider Jennifer's future there but stopped short of forcing her into special class for students with learning disabilities.

On the whole, my teachers made sincere attempts at being understanding. Some seemed afraid of epilepsy. They'd tell me not to worry about my homework or taking tests on time. Others were overly demanding and wouldn't accept reasons for late or poor work. After I fell down the stairs, I wasn't allowed to walk to or from classes by myself, and I had to leave classes early to avoid the rush of students. It was frustrating, but I never felt that I was being discriminated against.

"The problem for Jennifer is that, although she takes her medications regularly (many patients don't), she does have a lot of side effects," said Dr. John Kelly Sullivan, her current neurologist.

My memory stinks. There are parts of my life- things I've done, films I've seen, books I've read, people I've met- that I can't remember. One thing epilepsy did for me is that it showed me the value of the human brain.

Susan and I realized, as an Epilepsy Foundation pamphlet warns: "Severe and frequent seizures in a child inevitably put additional strains on the family, and even the most devoted and understanding parents are sometimes overwhelmed by the child's needs." Jonathan sometimes saw his older sister thrown to the floor and has disliked talking about it. "It was scary," he said.

Being epileptic means I may have a seizure anywhere, anytime. But I'm not going to worry about it or limit myself in where I go, or what I do, because of it. I am not defined by my disorder.

More tests yielded a refined diagnosis: Jennifer has what neurologists now call "juvenile myoclonic epilepsy." It is rarely outgrown, nor can the patient ever discontinue drug

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epsy. Jennifer takes Depakote and Diamox.

Even as Jennifer grew out of her teen years, we dared not let go too much too soon. In the spring of 1990, after earning honor grades at a prep school, Jennifer was accepted at Goucher College in Baltimore. I said goodbye at the Portland airport that fall with a hug I hoped could somehow protect her from the giant.

My parents occasionally have been overprotective: Don't swim. Don't ride bikes. Don't drive. Don't drink. Don't get stressed. Don't go sailing without a lifeline. Don't stay out late. Don't go near flashing lights (they could trigger seizures). Don't spend the night at a friend's home. Allow for seizure time in the morning. Don't walk up or down stairs unattended. Don't forget your pills.

I never thought the best solution was to live a limited life. I'd rather do things and take risks than do nothing at all. Going to college far from home wasn't something I felt afraid of. I felt very capable of taking care of myself.

She had 22 seizure-free months before the giant grabbed her in a dormitory shower. Another young woman found her and called me: bumps and bruises, no serious injuries, no bleeding. The call gave me a darker sense of frustration, but I realized that the caller's calmness had come from my daughter's careful explanations of epilepsy to her dorm mates. Jennifer was taking more and more responsibility for her life. I could not forever seek to shield her from all harm, I realized, nor should I try.

I feel that most people who know me should know that I am epileptic. I tell all my professors, because I may miss classes or have to make up tests. I tell dorm mates, because they should be forewarned. What to do and what not to do is something I explain to everyone I know. I try to explain what seizures look like, why I have them, what may set them off, what I'm like afterward. (I usually forget things.) Although I've felt frustrated and occasionally angry, I've never felt embarrassed by it. I have epilepsy, but epilepsy doesn't have me.

The giant returns less often now, and Jennifer is officially an adult. When she called home during the spring semester and told me, in a voice bubbling with excited pride, how she had been rockclimbing (in the company of skilled mountaineers), I felt the strength of her self-esteem and realized, finally, that the giant may cause her to stumble once in a while but will never stop her. A good thing for her parent to know.

For more information, write: Epilepsy Foundation of American, Dept. PP, 4351 Garden City Drive, Landover, MD. 20785. Or call 1-800-332-1000.

Source: From John Lovell and Jennifer Lovell, "I am not defined by my disorder," Parade Magazine, August 15, 1993, p. 6.

Hallahan, D. P. & Kauffman, J. M. (1997). Exceptional Learners: Introduction to Special Education. (7th Ed.). Allyn & Bacon: Boston, MA. p. 420-421.

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UNDERSTANDING SPINA BIFIDA:

Spina Bifida is a birth condition characterizied by an incomplete closure of the spine. Advances in treatment and management have enabled children born with spina bifida to live long and productive lives. They may have varying amounts of muscle paralysis, bladder and bowel problems, loss of skin sensation, and spine and limb problems. Most babies with spina bifida also develop hydrocephalus, the accumulation of fluid in the brain.

Although spina bifida has different forms and varying degrees of effect, most babies born with the condition will need surgeries to correct spinal, foot or leg problems; shunt surgery to drain fluid from the brain; application of techniques to control bladder and bowel function; and braces and other equipment to assist in walking.

With the help of parents and a team of doctors, therapists, teachers, and others, persons with spina bifida can achieve independence and enter the mainstream of their communities.

UNDERSTAND THAT:

- Spina bifida ("open spine") occurs when the spinal cord does not form properly during pregnancy.
- The causes of spina bifida have not been determined however, it is important to understand that it is not either parent's fault.

Spina bifida is caused by factors beyond their control.

- Spina bifida is not rare. It occurs in two of every 1,000 children born.
- There are three broad types of spina bifida: **lipomeningocele**, where a lipoma or fatty tumor is covered by skin and located over the lumbosacral spine; **meningocele**, where the covering of the spinal cord is pushed out in a section of the spinal column; and **myelomeningocele**, where both the spinal cord and its coverings are out of position.
- Since there are different types and severities of spina bifida, each person with the condition faces different challenges and may require different treatments.

MANAGEMENT:

The best way to manage spina bifida is a team approach. Members of the team may include neurosurgeons, urologists, orhtopedists, physical and occupational therapists, orthotists, psychologists, and medical social workers.

Specific treatments for people with spina bifida include:

- Surgery to close the child's back. This is usually done in the first 24 to 48 hours of life.
- Insertion of a shunt to drain excess brain fluid.
- Bracing and surgery to achieve standing and walking.
- Early and aggressive physical therapy to improve range of motion and to promote normal motor development.
- Bowel and bladder management programs, sometimes including intermittent catheterization.
- Psychological counseling to monitor the

child's mental status and emotional development.

MEDICAL TERMS TO UNDERSTAND:

Hydrocephalus:
The accumulation of fluid in the brain.

Lipomeningocele:
A lipoma or fatty tumor covered by skin and located over the lumbosacral spine.

Meningocele:
The covering (meninges) of the spinal cord is pushed out in a section of the spinal column.

Myelomeningocele:
Both the spinal cord and its covering are out of their normal postion.

CONTACT FOR HELP AND INFORMATION:

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
(312) 726 - 6200 (voice)
(312) 726 - 4258 (TDD)
(312) 726 - 1494 (FAX)
or the Easter Seal Society in your community.

Spina Bifida Association of America
4590 MacArthur Boulevard N.W., Suite 250
Washington, D.C. 20007 - 4226
(202) 944-3285

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Taking Big Steps

Stephanie Hergert, a talkative 7-year-old, was fitted with her first orthotic device at age 18 months. Born with spina bifida, she is paralyzed from the rib cage down.

Stephanie uses a wheelchair at the Coronado elementary school she attends, but at home she uses an orthotic device designed by Saxton, an owner of Southern California Orthotics and Prosthetics (SCOPe), which has five patient-care centers in San Diego County.

Saxton said he created the device by combining an Orlau Swivel Walker and a Rochester Parapodium. The parapodium holds Stephanie upright in a rigid, stable frame, and the base of the frame is mounted on swiveling foot plates.

By leaning forward and swinging her arms, Stephanie can move forward, Saxton explained. By leaning backward and swinging her arms, she can move backward.

"Five years ago, someone like Stephanie would not have had the opportunity to stand upright," said Stephanie's mother, Robin Hergert.

Indeed, the fact that her daughter can stand, let alone move with the aid of a brace, is more than Hergert ever expected.

"When she was born, the picture was grim," Hergert said. Doctors were very discouraging.

However, she said therapists and orthotists "gave us more hope."

Though the technology is available to custom-design devices such as Stephanie's, the cost to fund such devices is quite another matter.

Stephanie's brace cost close to $7,000. And Saxton said neither the state nor most managed health organizations cover the cost of high-technology devices, only basic or prefabricated devices.

Source: From Sharon F. Griffin, "Taking big steps," *The San Diego Union-Tribune*, February 13, 1994, pp. D1, D2. Used with permission.

Hallahan, D. P. & Kauffman, J. M. (1997). Exceptional Learners: Introduction to Special Education. (7th Ed.). Allyn & Bacon: Boston, MA. p. 426.

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Acquired Pediatric Brain Damage: Diverse Causes

Traumatic Causes

Every year 200,000 children sustain traumatic brain injuries; 89 percent of those injuries are caused by falls and by bicycle, motor vehicle, and sporting accidents. Other causes of traumatic damage include child abuse, gunshot wounds, and injury from other projectiles.[1]

Age is a strong predictor of the cause of brain injury in children:

- At least 80 percent of deaths from head trauma in children under 2 years of age are the result of nonaccidental trauma.[2]
- Preschoolers are the second highest risk group for brain injury.[3]
- Children between the ages of 6 and 12 are involved in twice as many pedestrian/motor vehicle accidents as younger children.[4]
- Youths, ages 15 to 25, are the highest risk group for traumatic brain injury; 220/100,000 youths under age 15 will sustain a head injury each year.[2] Teenagers, 14 to 19 years old, are most susceptible to sports and auto-occupant accidents.[4]
- Also, boys are two to four times as likely to sustain brain injury as girls.[3]

Nontraumatic Causes

Infectious diseases remain a major cause of neurologic disability in children, although early recognition and treatment substantially improve outcome. In one study, evidence of cerebral herniation was found in 25 percent of 302 children with bacterial meningitis.[5]

Environmental toxicity causes damage to many young brains. In a study conducted between 1976 and 1980, 700,000 children in the U.S. under age 6 were found to have elevated blood lead levels.[6] The effects of lead paint poisoning include learning disabilities, mental retardation, convulsions, coma, and death.[7]

Developmental abnormalities of the brain account for 30 percent to 40 percent of deaths during the first year of life. Surviving children sometimes develop intellectual impairments.[8]

Subarachnoid hemorrhage in a child with a history of seizure disorder usually suggests arteriovenous malformation(AVM). Mortality from bleeding as a result of AVM is less than that associated with ruptured aneurysms, but morbidity is higher. Periventricular-intraventricular hemorrhage occurs in 40 percent of infants born weighing less that 1500 grams.[5]

White matter abnormalities (perinatal leukoencephalopathies) are significantly higher in preterm infants. Cerebral palsy alone is 25 to 30 times greater in infants weighing less than 1.5 kg at birth. White matter destruction can also occur in children with meningitis. Cystic white matter lesions only occur in 3 percent to 7 percent of very low birthweight infants, but when these lesions occur, the association with cerebral palsy can be as high as 100 percent.[9]

Low birthweight infants have a high risk of developing bronchopulmonary dysplasia (BPD). In turn, these low-weight, BPD infants are twice as likely to develop respiratory illnesses that can lead to impaired neurologic and cognitive status.[10]

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SOURCE: Headlines, 1992, 3(5), p. 5.

Hallahan, D. P., & Kauffman, J. M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 390.

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THE STORY OF MY HEAD INJURY

I was 8 years old when I got my head injury. I was riding my bike on the sandpit road when a high school kid came around the corner and hit me. I don't remember anything about it. My brother Ian was with me and he saw the car smack me and me fly over the car into the bushes. My bike got run over cause the kid that hit me was drinking. And he didn't even stop until he saw my brother and his friends up the road. That's all stuff that Ian told me because I was unconscious.

I don't remember the hospital much. I remember my mom holding me and rubbing my head. My leg hurt the most cause it got broke in the accident. My mom says I was unconscious for 16 days and nights. She says they had to feed me with tubes and I had another tube to help me breath. Mrs. R. had the kids in school send me cards. My mom read them to me over and over. I wanted to be back in school real bad. I missed our Halloween party.

After I got home a teacher worked with me. Then I went back to school. I only remember how happy I was to be back. I didn't remember where my desk was. I guess I cried the first day cause everything was so hard and the kids were way ahead of me. My mom says I cried all week. I had to take two medicines for my head injury. I don't know what they were.

Now I'm in the 5th grade and I am doing much better. I got 2 B's, and 3 C's on my last report card. My mom says to say that it is still hard for me to read and think for a long time. As for me, I hate spelling. But I hated it before my head injury too. It takes me a while to get things and sometimes I have to bring work to my special teacher Mr. M. He helps me every afternoon for 45 minutes. When I first went back to school I saw him all afternoon. He says cause of me he is a head injury expert—Ha, Ha.

One thing I remember in grade 3 is not being able to stay awake long. I was tired a lot. I even fell asleep in school. And I hated lunch, not the food. But I got mixed up cause everything was so loud. Mrs. R used to let me eat lunch with her. This was good except she made me practice my math as we ate lunch.

I am suppose to tell you about my friends too. Ian, my brother, is still my best friend. He helps me with my homework and he is teaching me his computer. He said to say that I also have friends like Tommy, Jason, Franky, and Mica. We are on the same baseball team. We ride our bikes almost every day. I got a new bike after a year. My dad sent it from New York. My mom wasn't too happy about it. But I told her not to worry.

Right now I feel very good. I only take one medicine for my head injury. I think I am the same but sometimes it is still hard for me to learn stuff like reading for ideas and stuff. My teacher says I have come a long ways. Next year will be better, I hope.

The End,
Bobby G.

SOURCE: From An educator's manual: what educators need to know about students with traumatic head injury. National Head Injury Foundation, Southborough, MA: Author, 1988, pp. 89-90.

Hallahan, D. P. & Kauffman, J. M. (1994). Exceptional Learners: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 399.

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MUSCULOSKELETAL CONDITIONS

Some children are physically disabled because of defects or diseases of the muscles or bones. Even though they do not have neurological impairments, their ability to move is affected. Most of the time, muscular and skeletal problems involve the legs, arms, joints, or spine, making it difficult or impossible for the child to walk, stand, sit, or use his or her hands. The problems may be congenital or acquired after birth, and the causes may include genetic defects, infectious diseases, accidents, or developmental disorders.

Two of the most common musculoskeletal conditions affecting children and youths are muscular dystrophy and juvenile rheumatoid arthritis. Muscular dystrophy is a hereditary disease that is characterized by progressive weakness caused by degeneration of muscle fibers (Batshaw & Perret, 1986). The exact biological mechanism responsible for muscular dystrophy is not known nor is there any cure, at present. Juvenile rheumatoid arthritis is a potentially debilitating disease in which the muscles and joints are affected; the cause and cure are unknown (Bigge, 1991). It can be a very painful condition and is sometimes accompanied by complications such as fever, respiratory problems, heart problems, and eye infections. Among children with other physical disabilities, such as cerebral palsy, arthritis may be a complicating factor that affects the joints and limits movement. These and other conditions can significantly affect a student's social and academic progress at school. The box below describes how arthritis affected one child.

Tourette's syndrome. A neurological disorder beginning in childhood (about 3 times more prevalent in boys than in girls) in which stereotyped motor movements (tics) are accompanied by multiple vocal outbursts that may include grunting or barking noises or socially inappropriate words or statements.

muscular dystrophy. A hereditary disease characterized by progressive weakness caused by degeneration of muscle fibers.

juvenile rheumatoid arthritis. A systemic disease with major symptoms involving the muscles and joints.

Juvenile Rheumatoid Arthritis

"I feel more and more like a regular person these days," Amy Levendusky says. This is not the sort of thing a 9-year-old girl should have to say. But Amy has juvenile rheumatoid arthritis, which affects 71,000 children in this country. The disease gripped Amy at the age of 4 and spread from her feet to every joint in her body. "She'd be sitting there not able to move because it hurt so much," says her father, John. "I'd have to pick her up to take her from one place to another." Now a fourth grader, Amy attends a school outside her home district in Whitefish Bay, Wis., because it has an elevator. Most days she doesn't go outside for recess—even a bump might send a shock of pain through her whole body.

Still, Amy has shown signs of improvement in the last year. She has a daily regimen of joint exercises, and an anti-inflammatory drug called methotrexate seems to be helping. "There's not as much pain or stiffness most of the time," she says. "I can walk up the stairs normally now. Before, I had to pull myself up with my hands." She began piano lessons as therapy two years ago and discovered a love for the keyboard. "She just wants to be seen as a normal little girl," says her mother, Susan. But in one unexpected way the disease may have made Amy special. "I think she has developed a keener sensitivity," Susan says. "There will be times when she'll notice how beautiful things look outside and say, 'Let's take a walk.' Most kids her age wouldn't pay attention to things like that."

Source: From Melinda Beck with Mary Hager and Vern E. Smith, "Living with arthritis," *Newsweek*, March 20, 1989, p. 67. Copyright © 1989, Newsweek, Inc. All rights reserved. Reprinted by permission.

Hallahan, D. P. & Kauffman, J. M. (1997). Exceptional Learners: Introduction to Special Education. (7th Ed.). Allyn & Bacon: Boston, MA. p. 409.

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Juvenile Rheumatoid Arthritis

While most forms of arthritis happen in adulthood, the disease also is not uncommon in children. In fact, childhood or juvenile arthritis affects an estimated two hundred and fifty thousand children and young people in the United States.

The most common form of childhood arthritis is juvenile rheumatoid arthritis, which most often strikes children under the age of four. This arthritis may last a few years, after which time it usually goes into remission, which means that the symptoms disappear. However, about thirty percent of children who develop juvenile rheumatoid arthritis are left with permanent joint damage, and some suffer stunted growth. In addition, a few children continue to have active rheumatoid arthritis into adulthood.

Initial symptoms of juvenile rheumatoid arthritis usually include pain, swelling, or stiffness, in one or more joints.

Other common symptoms of juvenile rheumatoid arthritis include:

- a high fever;
- a rash;
- weight loss; and fatigue.

The disease may affect other organs and systems of the body, causing:

- vision problems,
- lymph node swelling,
- inflammation of the heart and lungs, and
- muscle weakness.

If a child has pain, swelling or stiffness, in one or more joints lasting longer than six weeks, you should be concerned about the possibility that he or she may have juvenile rheumatoid arthritis. These symptoms should be discussed with a doctor. In most children, the developing arthritis will be obvious, but in some children, particularly very young ones, an unexplained limp or avoidance of physical activity may be the first signs of arthritis.

If juvenile rheumatoid arthritis is diagnosed, treatment is available that can relieve symptoms, restore function of joints and prevent future joint damage.

Treatment for childhood arthritis should be closely supervised by the child's primary care doctor in consultation with other specialists in arthritis care.

Treatment may include some or all of the following:

- education and counseling for the patient and family, including
- reviewing methods of joint protection, splitting and rest;
- medications, which usually consist of anti-inflammatory and anti-arthritic
- drugs. More serious forms of arthritis require stronger medications;
- physical therapy, which includes water therapy, ultrasound and
- joint exercises. This therapy will help relieve arthritis pain,
- but more importantly, may help prevent or reduce joint damage
- and deformity;

- joint injection with cortisone and Novocain, which is only necessary
- in certain cases of juvenile rheumatoid arthritis. Joint injection can be very effective in treating persistent arthritis in one or more joints, which do not respond to other treatments; and
- surgery, which is rarely necessary in childhood arthritis. However,
- when other treatments don't work, surgery can be very effective
- in repairing or even replacing severely damaged or deformed joints.

In addition to following the treatments prescribed by the doctor, families can support children with arthritis by providing:

- a supportive environment in which stress is reduced;
- good nutrition and adequate periods of rest, and
- maintaining home, school and recreational activities as normally
- as possible.

With early diagnosis and appropriate treatment, juvenile rheumatoid arthritis can usually be well controlled. with most children, hopefully, entering adulthood with little or no permanent joint damage.

Search the Online Library for more information on Juvenile Rheumatoid Arthritis

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MUSCULAR DYSTROPHY

What is muscular dystrophy?

The term "muscular dystrophy" refers to a group of genetic diseases marked by progressive weakness and degeneration of the skeletal, or voluntary, muscles, which control movement. The muscles of the heart and some other involuntary muscles are also affected in some forms of muscular dystrophy, and a few forms involve other organs as well.

All forms of muscular dystrophy are caused by gene defects. What escaped scientists for decades was the identity of the responsible genes and the proteins they code for, as well as the ways in which those proteins are abnormal in these diseases. Many doctors once questioned whether the causes of muscular dystrophy could ever be found.

There are several different forms of muscular dystrophy. The major forms are myotonic, Duchenne, Becker, limb-girdle, facioscapulohumeral, congenital, oculopharyngeal, distal and Emery-Dreifuss. Each of these forms of muscular dystrophy differ in severity, age of onset, muscles first and most often affected, the rate at which symptoms progress, and the way the disorders are inherited.

In 1986, Muscular Dystrophy Association-funded researchers made medical history. A Boston-based team of scientists discovered the gene that, when defective, is responsible for Duchenne and Becker muscular dystrophies. One year later, the same research team identified the crucial protein-dystrophin- which, if deficient or abnormal, causes both diseases. These breakthroughs were the culmination of many years of painstaking research by MDA grantees.

A new and more hopeful era has emerged with these milestone achievements. MDA-backed scientists are using state-of-the-art research techniques, like those that led to the Duchenne muscular dystrophy gene and dystrophin breakthroughs, in their search for the causes of the muscular dystrophies and other genetic neuromuscular diseases. Gene and protein defects for many of these diseases have now been identified.

In the short term, gene identification leads to better diagnostic tests and a better understanding of the biological basis of the disease. In the long run, these discoveries will likely lead to disease treatments.

Does muscular dystrophy affect children exclusively?

No. Muscular dystrophy can affect people of all ages. While some forms first become apparent in infancy or childhood, others may not appear until middle age or later. With improved medical care, particularly of problems affecting the heart and lungs, children with muscular dystrophy are living further into adulthood than ever before.

What causes muscular dystrophy?

Flaws in muscle protein genes cause muscular dystrophies. Each cell in our bodies contains tens of thousands of genes. Each gene is a string of the chemical DNA and is the "code" for a protein. (Another way to think of a gene is that it's the "instructions" or "recipe" for a protein.) If the recipe for a protein is wrong, the protein is made wrong or in the wrong amount or sometimes not at all.

Are muscular dystrophies always inherited?

Muscular dystrophies are generally inherited but in some cases no family history of the disease may exist.

Is muscular dystrophy contagious?

No. Genetic diseases aren't contagious.

Information taken from the Muscular Dystrophy Association homepage: http://www.mdausa.org

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Table 10–2 Additional Physical Conditions

CONDITION	DESCRIPTION
Asthma	Chronic respiratory condition characterized by repeated episodes of difficulty in breathing, especially exhalation
Cystic fibrosis	Inherited disease characterized by chronic respiratory and digestive problems, including thick, sticky mucus and glandular secretions
Diabetes	A hereditary or developmental problem of sugar metabolism caused by failure of the pancreas to produce enough insulin
Nephrosis and nephritis	Disorders or diseases of the kidneys due to infection, poisoning, burns, crushing injuries, or other diseases
Sickle-cell anemia	Severe, chronic hereditary blood disease in which red blood cells are distorted in shape and do not circulate properly
Hemophilia	A rare, sex-linked disorder in which the blood does not have a sufficient clotting component and excessive bleeding occurs
Rheumatic fever	Painful swelling and inflammation of the joints (typically following strep throat or scarlet fever) that can spread to the brain or heart
Tuberculosis	Infection by the tuberculosis bacterium of an organ system, such as lungs, larynx, bones and joints, skin, gastrointestinal tract, genitourinary tract, or heart
Cancer	Abnormal growth of cells that can affect any organ system

Hallahan, D. P. & Kauffman, J. M. (1994). Exceptional Children: Introduction to Special Education. (6th Ed.). Allyn & Bacon: Boston, MA. p. 405.

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Cancer

Editor's Note: The following is a true story by a student at Albemarie High School.

Cancer! Brain tumor! Malignant! To most people, when these words are pronounced, they perceive it as a death sentence and immediately lose hope. Shock, disbelief, and denial are initial reactions. People believe, "It can't happen to me. I'm too healthy." Cancer and diseases are a part of our everyday life. Cancer can happen to anyone, me or you. In fact, it did happen to me.

Five years ago, I was diagnosed as having a brain tumor. My reaction was, I expect, typical. "Why me? Will I live or die? It can't be happening to me, of all people."

I was almost ten years old and I wasn't ready to give in to this major setback in my life. I guess that's why I'm alive today. I fought against the disease instead of quitting before the battle begun. I had a positive attitude and knew I had a lot to offer. My whole life was ahead of me and there were goals I wanted to accomplish like going to college, getting married, and having a family.

Before I had a brain tumor, my lifestyle was far different from what it is now. I was popular and was one of the best athletes in my class. I played soccer, basketball, baseball, and was an excellent swimmer; all the while I had good grades also. My goal was to do the very best I could in everything. I thought I had the most perfect life a kid could want at that age. But one day, I started having excruciating headaches and nausea. I had just had a yearly check-up and the doctor said that everything was normal. Yet my headaches and sickness continued eventually becoming so severe that I was taken to UVA and Martha Jefferson hospitals, and the doctor's office for numerous tests, including bloodwork, an EEG, and neurological work-ups. The tests revealed nothing. Finally, my symptoms changed dramatically. My headaches became unbearable, I was combative, disoriented, and did not know anyone. The doctor ran a CAT scan and he found that I had an abnormal cell that was growing out of control in my brain and it was cancerous. He told my parents that I might not make it and that surgery as well as extensive follow-up therapy such as radiation would be necessary.

The illness put a lot of pressure on my parents and me. There were numerous trips to the hospital to see a number of doctors and huge medical bills. Because of a loss of my motor abilities there were things such as writing that I could no longer do which presented a problem with even the tiniest task I undertook. I lost my hair and to help relieve my double vision I had to wear an eye patch over one eye. I had to face my family, friends, and school knowing that I had cancer and that people couldn't help but think that I might die.

My parents and I were fortunate that we had a lot of friends that gave us not only moral support but they helped out with errands and chores so that my parents could spend as much time as possible with me. They were constantly fixing meals, running errands, and doing chores and especially praying for me and my family.

It was a frightening and difficult time, but the funny thing was that I never thought that I was going to die. It may sound sort of weird, but I had faith-faith that I could overcome the odds and someday I would be as good as before I became ill.

I had to face many struggles. After I went through surgery, I realized that my head had been shaved so that the doctors could see the area more clearly. The surgery lasted five and one-half hours. I was in intensive care for less than a day, a shorter time period than the doctors had predicted. The doctor said that I had a little paralysis in my left eye causing double vision and my motor skills were impaired. I had to undergo radiation for thirty-one days, physical and occupational therapy helped me to improve the motor skills that I had lost, such as writing, walking, balancing, etc. I had to have radiation so that the disease would not return and also to make sure that abnormal cells did not spread to other parts of my body. The radiation destroyed many of the good cells with the bad cells, but it did not make me sick.

The effects of the illness still aren't over. People, especially other kids, treat me differently since I've had cancer. They tease me about how I can't do things as well any more or that I look different because of my thinning hair or double vision. It's almost as if they're afraid

of me.

I wish people realized that cancer is not contagious and that people who have cancer just want to be treated the same as everyone else. They still like to talk to their friends, play sports, have girlfriends and boyfriends, and goof-off. At times, having cancer made me feel like a handicapped person-lonely and that people just don't understand. I've seen that cancer causes children and young people to grow old before their time and I feel like I missed out on being a kid. Now life has a different meaning to me, because I almost lost it. I don't take things for granted and I live each day knowing that no one is promised a tomorrow.

Having cancer, I lost my popularity and good athletic abilities, and I thought I had lost everything that was ever important to me. It took a while, but then I realized that I was wrong. I had my new health, my new life, and my parents. That's a lot. I also gained a new perspective on life: caring for others. Now when I see people who are disabled or different from everyone else, I compare them to me and how my life would be in that situation.

To some people, cancer, a disease, or a handicap are reasons to give up, stop trying, but to a kid who's been there, I'm with W. Mitchell, a paralyzed millionaire who says, "All limitations are self-imposed. It's not what happens to you in life, it's what you do about it." For me, I've learned to live with life's limitations, even cancer, and I've learned that you can overcome those limitations if you put your mind to it.

Source: By Matt Radcliffe, "The Patriot," 1/19/90, p. 11.

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XVI. Attention Deficit Disorder

- The Hyperactive Child
- ADD and Hyperactivity in the Classroom

Special Parent ★ Special Child

Practical pointers for parenting handicapped children

VOL. 3, NO. 5 SEPTEMBER/OCTOBER 1987

THE HYPER-ACTIVE CHILD

". . . My child is in constant motion; he was a fussy baby and now that he's older he still can't seem to settle down. He flits around from one thing to another but doesn't appear to be interested in anything for very long. He's not a **bad** child—it's just that he's so disruptive and distractible he can't follow directions or obey any rules. He's so bossy that he's always in trouble in school with classmates, his teachers and the rest of the neighborhood. We love him, but wherever he goes there's chaos. I've always figured he was a hyperactive child but the doctors say he has **attention deficit disorder—ADD**. Pinning a label on my son doesn't help him behave any better or make life easier either. Somewhere inside this bleak picture there is a little boy we love, but how are we going to help?"

In response to many reader inquiries similar to the one above, this issue will examine the problem of hyperactivity and the best ways of dealing with the hyperactive child at home and at school.

What causes hyperactivity?

No one is quite sure of the cause but psychiatrists and other doctors, puzzled by otherwise healthy children whose misbehaviors and persistent distractibility couldn't be attributed to any problem in the home, theorized that somehow it is inborn in the child. More boys than girls are affected, and it is estimated that from three to five per cent of all children are hyperactive, to some degree or other.

Although there is no firm evidence, some clinicians feel that neurological immaturity or an inherent genetic problem might be the cause. Even fetal exposure to harmful substances such as environmental pollutants or food additives has been considered as the possible culprit.

However elusive the cause, hyperactive children who are suspected of having ADD share similar patterns of behavior.

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Patterns of behavior

The ADD, hyperactive child generally has a **short attention span** and is easily distractible. The child with this problem doesn't seem to be able to complete any task unless given one-to-one direction. Often parents find themselves in endless confrontations, nagging constantly, "Finish your homework, finish the dishes, you didn't finish making your bed." The hyperactive child is so distractible he literally seems to suspend his activity in mid-air, going on to something completely different, oblivious to the tasks he's left undone or half completed.

He is extremely impulsive. "He wants what he wants when he wants it." Taking other people's possessions without heeding the rightfulness or wrongness of his actions, running into traffic to retrieve a ball with no awareness of the inherent dangers, inability to profit and learn from previous mistakes are all examples of behaviors that lead to troublesome family relations. Acting without forethought is coupled with punches, fist fights and verbal confrontations with siblings or playmates who refuse to play the game his way. He has difficulty conforming to rules or waiting his turn, demanding instant gratification of his needs.

The hyperactive child is disorganized. He often is unable to plan effectively or carry through to completion even simple tasks on his own. He often appears disheveled, shirt tails flapping, laces untied, and, moreover, is often unaware or unconcerned that this is the case.

The hyperactive child appears to be on the move. He seems driven by some constant inner need to touch, tap, fidget, squirm, push, knock over or kick. It's as if his body is in high gear at all times, with a marked inability to shift into low.

As an infant he was a poor sleeper, seldom napped, awoke at the slightest sound, slept fitfully and never through the night. These sleep disturbances often continue unabated as he grows older.

As a toddler he was not only into everything but there was seemingly little purpose to his ceaseless activity. Toys were not played with; they were broken or thrown. Books were ripped and attempts to engage him in shared play or story telling met with fidgets, squirms and outright running away. Whereas a normal toddler can sit quietly for at least short periods of time to color or put together a puzzle, the hyperactive toddler is unable to sustain any play activity for more than a few seconds. Crayons are broken and puzzle pieces discarded in his wake as he flits to yet another activity. One harassed mother described her child as "a disaster waiting to happen."

Although many active toddlers appear to behave in a similar fashion, the major difference between the normal toddler and the hyperactive youngster is that the normal child is able to lower his activity level, listen for direction and, most tellingly, is able to **stop** on his own.

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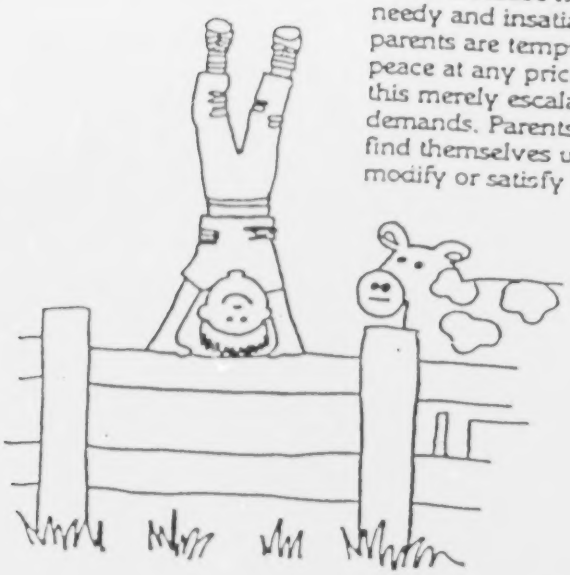
During childhood the hyperactive youngster continues to fidget, is unable to sit through a meal, for example, or even watch a favorite TV program without roaming around the house. Teachers at school report he is unable to sit at his desk and that he speaks out of turn and frequently annoys others.

Difficulties in coordination are often noted. Many hyperactive children appear somewhat gawky and less coordinated than their peers. Throwing or catching a ball and other activities requiring hand-eye coordination are problems for them. However, many hyperactive youngsters excel in sports such as swimming where this is not a factor. Typically, the hyperactive child has serious difficulties in activities involving finger dexterity such as handwriting, coloring, cutting with scissors and other school-related tasks.

Attention-demanding behaviors cause grave concern both at home and at school, for the hyperactive child demands center stage at all times. Because he appears so needy and insatiable, guilt-ridden parents are tempted to pay for peace at any price. Unfortunately, this merely escalates the child's demands. Parents and siblings find themselves unable to control, modify or satisfy him. The foot-stamping, whining, into-everything toddler becomes the driven, annoying, demanding, show-off child or adolescent.



The hyperactive child is, above all, domineering. He insists on being first in line at school and served first at the dinner table at home. He frequently sees himself as the "boss," barking orders indiscriminately, resisting all rules and regulations not his own. Siblings and friends find him a difficult companion. Games must be played his way or not at all. He is often aggressive and becomes known as the playground bully. He upsets others to the point where he is virtually friendless, unless he finds younger children who are more likely to tolerate his bossiness.

He often lacks judgment which manifests itself as total fearlessness, swinging from trees, playing on or near railroad tracks, annoying animals to the point of endangerment.

The hyperactive child is often beset with mood swings. He appears elated one minute, despondent the next, with no rhyme or reason or direct relationship to anything in the environment that could cause such sadness or joy. Parents find themselves at wits end trying to provide him with stability or comfort. Even minor incidents in their hyperactive youngster's life can trigger major temper tantrums. The hyperactive child is over excitable and short-fused, with such low frustration tolerance that even the most mundane events often produce prolonged loss of control.

The end result of a hyperactive child's driven behavior is ultimately a child at odds with himself and the world—endlessly wronged, different, friendless, a saddened child with little or no self-esteem.

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How can we help?

ABOUT THE AUTHORS

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Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

Medical treatment. The first step is to seek medical advice if your child displays any or all of the above troublesome patterns of behavior. Dismissing your youngster's problems as just garden-variety hyperactivity or ignoring the problem will not help, especially if the hyperactivity is masking other underlying causes. Only a physician skilled in diagnosing this type of disorder should make a definitive diagnosis.

Hospitals and clinics that offer a multidisciplinary team approach—including the services of a pediatrician, neurologist, psychologist, psychiatrist—are best. These specialists will examine your youngster, go over his previous medical histories, and after a thorough review will have a conference with you to disclose their findings. If they diagnose your child as hyperactive ADD, they will design a course of treatment and will monitor your youngster to make sure he is being helped.

One form of medicine or treatment plan that is helpful to one child might not work with yours. It is vital to **stay connected to your child's medical team** for frequent updates, especially as he grows older and his metabolic needs change.

Medicines are often indicated. Many hyperactive children react positively to certain specific drugs. Frequently, this is the only kind of treatment necessary to bring the child to full functional ability. Most parents are uncomfortable with the idea that their youngster requires medication, especially for any length of time. The best attitude to adopt is that, for all intents and purposes, hyperactivity is a physical problem and that medicine is required to control the disorder much as if the child had diabetes or seizures and needed medical treatment for relief.

Two types of medication are frequently indicated. The most commonly used are **stimulant drugs** such as Ritalin®, Cylert®, or Dexedrine®. Although stimulants, these have the paradoxical effect of calming down hyperactive children. They increase the child's attention span, reduce jittery behaviors and help the child manage better at home and school.

Occasionally **major tranquilizers** such as Mellaril®, Haldol®, and Stelazine® are indicated, especially when the child has sleep disturbances or intense feelings of anxiety.

As with any medication, parents should follow dosage directions carefully. The child should be observed closely and the doctor should be contacted if there are any changes. Drugs have possible side-effects and parents should be aware of the effects, if any, of long-term dosage.

Diet. The possiblity that certain foods or sensitivity to food additives or other allergies can cause hyperactivity remains controversial. Special diets, it is claimed, have helped children. In specific circumstances some food substances can cause behavioral symptoms. Sugar, food dyes, and other additives have been suspected as offending substances for susceptible children. As this is very difficult to document, parents are advised to consult a pediatrician, an allergist, and a medical doctor specializing in nutrition before undertaking any

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special diets or vitamin therapies for their hyperactive child. A balanced diet, low in sugar and fat but with plenty of fresh fruits, vegetables, whole grain products, lean meats, fish, and milk products should benefit the entire family.

Psychological help. Often the hyperactive child responds to psychological help. The disorder has the effect of harming the child's self-esteem and ability to form friendships to the point where psychological intervention is often indicated.

Most hyperactive children are unhappy about their runaway emotions and loss of control. They seek protection from their own impulsive drives—they need parents who can limit as well as love.

This is easier said than done, of course. Parents should seek support groups and avail themselves of professionals who can help set up a consistent program of behavior modification. The use of praise and rewards in working on those behaviors that are most troublesome requires help from trained experts.

Do's and don'ts

- **Do remember that teaching self-control is a must.** Saying to your child and others, "Johnny can't help it, he's hyperactive," will only serve to reinforce Johnny's inappropriate behaviors. Hyperactive children respond best to structure and external limits that are fair, uncomplicated, and consistent. Expecting appropriate behavior and compliance to a simply-stated rule for a minimal task or time frame is a good way to start.
- **Do accentuate the positive.** Find some simple activity that your child genuinely enjoys. Praise him often for any positive behaviors you observe. Most often, hyperactive children function best in a one-to-one situation, free from external distractions or noise.

A hyperactive child, above all, needs someone caring enough to organize, plan, supervise, and provide the structure he cannot organize on his own.

- **Do encourage your hyperactive child to engage in activities** that will burn off excess energies—for example, jogging, track, long-distance running, swimming laps and other endurance sports that don't require hand-eye coordination.
- **Do be aware that hyperactive youngsters** are frequently insensitive to pain and can sustain cuts and bruises with little discomfort. Parents should also be aware, however, that **overreaction** to minor hurts is an attention getting device.
- **Do keep outside stimulation to a minimum.** Hyperactive children cannot screen out environmental noise or movement, frequently reacting to even normal household sounds with adverse reactions. Blaring TVs, whirring household appliances, even people conversing in normal tones are distracting enough to trigger frantic behavior.
- **Do adhere to a consistent schedule.** Having dinner, bedtime and other activities at reliable times can ease some of the disorganization.
- **Don't overload your youngster with too many things at once.** Avoid giving too many directions. "Make your bed, get dressed, come and eat breakfast,

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we're leaving soon," is too much for an ADD child to handle. Select one activity at a time, provide plenty of supervision and verbal praise for successful completion of just one task.

• **Do promote your hyperactive child's self-esteem.** Encourage him to participate in an activity he enjoys and make sure he receives recognition for it. Be on the lookout at all times for any opportunity to boost his ego.

• **Do provide supervised recreational experiences for your child.** Free time is often the worst time of all. A swim club, horseback riding instruction, even a short walk together are alternative ways of providing organization for him.

• **Do see him as a child capable of surmounting his difficulties.** Don't blame or deny. Be honest with him about his difficulties but let him know that you love him and that the whole family will work together to help achieve as much of his potential as possible.

THE READER ASKS . . .

QUESTIONS AND ANSWERS

We invite inquiries or hints from our readers. If you have a question, a problem or comment about any aspect of parenting special children, write to:

Special Parent/Special Child
Lindell Press, Inc.
P.O. Box 462
South Salem, NY 10590

Q. "My son, age 5½, is only partially toilet trained and continues to soil his pants. Even though he seems to know what is expected of him, he won't do it. Can you give me some suggestions?"

A. The easiest and most effective method involves the use of behavior modification. First try to establish the times of the day your son usually eliminates. If your child is not afraid of the toilet and is willing to sit on a potty chair, then place the child on the toilet during the times when there is the greatest probability he will go. If he does, reward your child with praise, a hug, and some other reinforcement, e.g. food tidbits your child likes. Becoming angry or punishing your child for soiling himself might very well be counterproductive. It may take a bit of time, but, assuming there is no physical or serious mental problem, this procedure can be very useful. You may wish to consult a professional for additional help and guidance.

Q. "We've just been told that our son, age 6, is developmentally disabled. He is unable to cut with scissors or even color. We can't tell if he is right or left-handed as he doesn't use either hand consistently. What causes this? What can we do to help him?

A. Developmental disability is a catchall term that includes a number of very different disabilities. It is important to pinpoint your son's problem as much as possible. A thorough medical and neurological evaluation would be the first step. The next would be a complete psychological and educational assessment. Based on these evaluations and with the help of your school district, you should be able to find an appropriate program for your child, one that is specifically designed to meet his needs.

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Psychologist's corner: ADD & HYPER-ACTIVITY IN THE CLASSROOM

by George Popper, Ph. D.

David is an attractive, verbal, six-year-old. He comes from a good home and lives in a nice neighborhood. When you first see him, he looks normal in every way. But David has a problem.

In school, David's teacher says he is doing poorly; he is very distractible, disruptive, and can't seem to sit still. He had been referred to the school psychologist who spent time observing David in the classroom, talking with his teacher and his parents and giving him a variety of psychological tests. As everyone suspected, David's tests showed that he was very bright. True, his academic scores were somewhat low, but not that low. The psychologist felt that there was no evidence of a serious emotional problem or problems at home. However, David's mother did confide that her son is much more active than other children his age and that she often has a hard time controlling his behavior at home. She went on to say that other children don't like to play with him because he always gets into fights with them. She talked to her pediatrician but couldn't get a definitive diagnosis and she's still looking for some answers.

Although the diagnosis is a difficult one to make, there is a good possibility that David is a hyperactive child. His hyperactivity could also be a symptom of something known as Attention Deficit Disorder or ADD. There are many unanswered questions about hyperactivity but investigators have begun to uncover some of the mysteries of this complex problem. At one time, i fact, ADD had been known minimal brain dysfunction. Research has shown that ch with ADD may or may not b hyperactive and, to a large e a diagnosis of ADD or hyper ty is based on clinical judgm

Children with ADD are pr learning problems, but the k problems ADD children disp are very different from other kinds of learning disabilities. Often their learning deficienc are not as severe or as clear-c LD children so that children ADD seem to slip between th cracks of our educational sys To make the matter more cor plicated, there are children w are emotional disturbed or w are hyperactive **without** hav ADD. For simplicity, this artic will focus only on the child v ADD and hyperactivity (ADD

What kind of special probl do ADDH children have? The problem is diagnosis. Often, t children are seen as emotiona disturbed and are mistakenly treated as such. One of the m problems that ADDH children counter is peer rejection. This jection can result in a negativ self-image which in turn can tribute to emotional problems Often, but not always, childre with ADDH are clumsy and p athletes. In boys, this further distances them from their pee Although ADDH is frequently associated with neurological p lems, sometimes these can be determined medically and sometimes not. The child's environment often contributes to

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problem, but in most cases a child with ADDH would have the problem regardless of the environment. This is important to understand since parents and teachers often perceive the ADDH child as being willfully "bad;" this is rarely the case. The ADDH child is not misbehaving on purpose! This is not to say, however, that the ADDH child can't be taught to exercise better impulse control or improve his attention span.

ADDH children all need a well-structured, predictable school environment. Because these children are highly distractible, they have particular difficulty with excessive stimulation—either emotional, physical, or sensorial. When the ADDH child is being taught something new, keeping all stimulation at a low level tends to reduce the level of hyperactivity. Recent studies have demonstrated the effectiveness of biofeedback in helping ADDH children complete classroom assignments. Using biofeedback machines, ADDH children are first shown how to relax and how to make their bodies relax. The hyperactive children who participated in the relaxation training program and who were trained to use biofeedback while doing classwork tended to show more improvement than ADDH children who did not receive the training. What was most important was not the biofeedback per se, but that the children shared directly in the management of their behavior.

Other successful methods include having the ADDH child self-evaluate his own behavior. In one such procedure in which inattention was the identifed problem, the teacher signaled the child to record his inappropriate behavior on a special data sheet. When used in the classroom, this method was found to be effective in improving attentiveness. This approach is a bit different from more traditional behavior modification programs and again points to the importance of having the ADDH child share in the responsibility of dealing with his behavior.

Does psychotherapy help or is medication enough? The need for medication must be determined by a qualified physician who has had either training or experience with this special problem. Medication has been very effective, but other approaches are valuable. Children with ADD often need someone they can trust and in whom they can confide. They need to understand the nature of their problem and to know that there is much they can do to help themselves. Parents and families are often frustrated and overwhelmed and they, too, are in need of support, guidance, and good information.

RELATED ISSUES OF SPECIAL PARENT/SPECIAL CHILD:
- Behavior, Part I
- Behavior, Part II
- Behavior Modification

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XVII. Disability Related Web Sites

Disability Related Web Sites

Peer Tutoring

Metropolitan Nashville Peer Buddy Program:
http://peabody.vanderbilt.edu/SPED/projects/buddy/home.htm

Mental Retardation

American Association on Mental Retardation:
http://www.aamr.org/

National Association for Down Syndrome: NADS
http://www.nads.org/

Association for Retarded Citizens: ARC
http://TheArc.org/welcome.html

Autism

Family Village Page on Autism
http://www.familyvillage.wisc.edu/lib_autm.htm

Autism Research Institute
http://autism.com/ari/

National Autism Society
http://www.oneworld.org/autism_uk/

ADHD

ADHD Help Page
http://www.jdanda.com/users/adhd/

FACT'R
http://www.add-plus.com/

ADD FAQ Site
http://www3.sympatico.ca/frankk/

Cerebral Palsy

Cerebral Palsy Fact Sheet
http://www.ucpa.org/html/research/factsfigs.html

United Cerebral Palsy Association
http://www.ucpa.org/html/

Hearing Impairments

Hearing and Speech Deafness Center
http://www.hsdc.org/

Gallaudet University's Home Page
http://www.gallaudet.edu/

The Central Institute for the Deaf
http://cidmac.wustl.edu/

Language Impairments

American Speech-Language Hearing Association
http://www.asha.org/

Wolfe Products
http://www.wolfe.net/~dr_bill/speech2.html

Physical Impairments

Cure Paralysis Now
http://www.cureparalysis.org/

DO-IT at the University of Washington
http://weber.u.washington.edu/~doit/

Visual Impairments

Blindness Resource Center
http://www.nyise.org/orgs.htm

American Council of the Blind
http://www.acb.org/

US National Federation of the Blind
http://www.nfb.org/

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*Fact sheets were adapted from the National Information Center for Children and Youth with Disabilities (NICHCY). Also, materials were adapted from Step by Step: A guide for parents by the Tennessee Department of Education, Division of Special Education.